



**Observatory for  
Sociopolitical Developments  
in Europe**

# **National dementia strategies – a comparative approach in Europe**

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# 1 BACKGROUND

Dementia has been an issue right at the top of the political agenda for many years now. It was prioritised at European level in 2011 when the European Parliament called for the member states to "*come up with specific national plans and strategies for Alzheimer's disease*". Such strategies should take account of the social, health and political consequences of dementia and support the families and the people themselves in the best possible way.

Efforts are also being made at a global level. For example, the First WHO Ministerial Conference on Global Action against Dementia was held in Geneva in March 2015. Health ministers, researchers, clinicians and NGO representatives came together in Geneva to discuss the changes to be expected in view of the increasing number of people with dementia. Everyone agreed that more research, better health care services and more support for (care-giving) relatives was needed. The WHO currently forecasts that the number of cases around the world will triple by 2050, from 47 million today to 135 million.

## 1.1 Objectives

This working paper focuses on the implementation of strategies in countries that have already launched one or more programmes. Its objective is to identify similarities and differences in how the strategies are implemented and to use these findings to pinpoint the positive and negative factors for implementation. The results can then be used as a basis to derive fundamental recommendations for further action in Germany and to further develop the agenda (*Allianz für Menschen mit Demenz*).

The findings were gained by analysing documents, conducting research in the selected countries and obtaining information through direct contact with the stakeholders involved (ministries, federations, Alzheimer associations or organisations, universities etc.).<sup>1</sup>

## 1.2 Countries selected for the comparison

The dementia strategies analysed below are those of France (2014-2019), Scotland (2013-2016) and Switzerland (2014-2017).

Both France and Scotland already have dementia strategies in place. France's first strategy dates back as far as 2001, whilst Scotland adopted its first strategy for the years 2010 to 2013. Scotland and France have therefore already developed strategies of the second and fourth generation respectively, and have evaluated preceding ones for the purpose. It can hence be assumed that these countries have a respectable level of expertise in implementing strategies and that this can be used as a significant learning factor for the situation in Germany.

The Swiss strategy was published only last year; it is the country's first national strategy. The assumption here is that a comparison with Germany will be useful due to the similar federal

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<sup>1</sup> The literature cannot be researched in any detail because hardly any papers on the implementation of national dementia strategies have been published to date.

structures of both countries. The question of how existing strategies in the states of Germany are implemented compared with how the strategies already in place in the cantons of Switzerland are handled should be of particular interest.

### 1.3 Fields of action

Research<sup>2</sup> in secondary sources identified overlap in the following fields of action:

- raise social awareness of dementia, removing stigmas and providing information
- improving diagnosis, partly by integrating early advice and assistance
- improving care and support at home
- raising the qualifications and skills of professional staff and volunteers
- promoting research (both medical and care and nursing research).

This working paper will analyse three different measures which can be allocated to three meta-level categories.

### 1.4 Potential implementation action and comparative criteria

Pilot projects, the formation of networks, sponsorship programmes, legislation and publicity campaigns are examples of potential means of implementation. The strategies were analysed and compared according to the following criteria:

- scope of execution and implementation
- interaction between stakeholders
- form and nature of funding
- creation of a monitoring body and any other experiences made during implementation (e.g. by means of evaluations)
- status of implementation of the measure

## 2 FRANCE

France's first national dementia strategies are depicted in a brief excursus (under 2.1). The framework conditions and the fields of action in the fourth (current) strategy are discussed in section 2.2. Section 2.3 reviews the status of implementation. Section 2.4 describes a measure called MAIA, which serves as a new organisational approach.

### 2.1 Excursus: France's first three national dementia strategies

In 2001, France became the first European country to develop a national dementia strategy. It ran from 2001 to 2005 and had six goals: 1. Identify early symptoms of dementia and refer patients to specialists at an early stage. 2. Establish memory centres to enable early diagno-

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<sup>2</sup> e.g. Kirchen-Peters, S.; Hielscher, V. (2012): *Expertise "Nationale Demenzstrategien". Vergleichende Analyse zur Entwicklung von Handlungsempfehlungen für Deutschland*. Institut für Sozialforschung und Sozialwirtschaft e. V. Saarbrücken; Available at: [www.iso-institut.de/download/Nationale\\_Demenzstrategien\\_Endbericht\\_BMFSFJ.pdf](http://www.iso-institut.de/download/Nationale_Demenzstrategien_Endbericht_BMFSFJ.pdf).

ses. 3. Lay down ethical guidelines for affected families and the care facilities concerned. 4. Provide financial support for those affected, offer day care facilities and establish local information centres. 5. Construct new nursing facilities and improve existing centres. 6. Promote research and encourage clinical studies.

The second strategy was launched in 2004 and ran for three years (2004-2007). Four new elements were added to the six aims in the first strategy. These particularly concerned the expansion of insurance coverage for people with dementia, support for younger sufferers, training for professional staff and volunteers, and the establishment of "emergency shelters".

The third strategy ran from 2008 to 2012 and enjoyed a quite substantial budget of € 1,6 billion. The strategy covered three key areas, under which eleven objectives and 44 specific measures were formulated.

This third strategy was evaluated in 2013 and the findings published in a 100-page report. It referred to the achievements of the strategy in the fields of research, diagnostics and support for people with dementia and their families. It also recommended 56 measures to be taken in future.

Due to the extensive findings of the evaluation, the fourth strategy took some time to develop. This meant that there was not a valid strategy in place between 2012 and 2014.

As France has been concerned with dementia strategies for some 15 years now, it can be assumed that the country has great expertise.

## 2.2 Framework conditions

The new, fourth strategy was presented by Marisol Touraine, the minister for social affairs, health and women's rights, with two secretaries of state on 30 October 2014. The strategy is to run for five years, from 2014 to 2019.

The first noticeable difference to previous strategies is the title, "*Plan Maladies Neuro-Dégénératives 2014-2019*"; it has become a strategy that now implicitly covers other neurodegenerative illnesses.<sup>3</sup> Apart from Alzheimer's, the strategy names Parkinson's disease and multiple sclerosis as further neurodegenerative illnesses whose prevalence is likewise on the increase. Some 850,000 people suffer from Alzheimer's in France today, around 150,000 from Parkinson's and approx. 85,000 from multiple sclerosis.

The fourth strategy is composed of 4 fields of action, 12 challenges<sup>4</sup> and 96 specific measures. The 4 strategic fields of action are:

1. providing life-long care and support and in all matters throughout France (diagnosis and care)

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<sup>3</sup> According to the editorial, President Hollande has, since the start of his term of office in 2012, been keen to reach the next level and to develop a comprehensive, global strategy.

<sup>4</sup> The previous strategies spoke of objectives. The term *enjeux* (challenges) is used in the current strategy.

2. promoting social acceptance and knowledge about the challenges posed by neurodegenerative illnesses, and cushioning the personal and social consequences which result in everyday life (care and the removal of stigmas)
3. further developing and coordinating research into neurodegenerative illnesses (research)
4. using governmental action in the form of the new plan as an innovative, effective tool for influencing policy programmes and encouraging democracy in health services (evaluation and control).

Among other things, the first field of action aims to improve diagnoses, promote a multi-disciplinary approach to the provision of care and arrange for better training for health care professionals in order to raise the quality of care. According to a study made by *Cap Retraite*<sup>5</sup> in May 2015, only half of the sufferers in France have actually been diagnosed with the disease.

The second field of action specifies challenges: increasing the autonomy of patients, encouraging respect in dealing with them, improving care and assistance at home, and improving support to care-giving relatives.

The third field of action concerns (medical) research in future. This is to be stepped up in order to better understand the illnesses and decelerate both the appearance of noticeable symptoms and the advancement of the diseases.

The fourth field of action determines that implementation should be overseen by an advisory committee and be subject to evaluation.

The 124 pages of the strategy do not contain any graphics or illustrations. The cover, however, is elaborately laid out in colour, with logos and the symbol marking it as a national health strategy. The fields of action, the challenges and the specific measures are described without particularly embedding these in the subject matter. The strategy is thus rather aimed at experts already well-versed in the topic.

As reasons for expanding the plan to cover other neurodegenerative diseases, the introduction names the exploitation of synergies and the similar, common symptoms and characteristics of the illnesses.<sup>6</sup> This apparently prompted the government to favour an overall, integrated concept in order to tackle the medical and social challenges.

With the strategy extended to include multiple sclerosis, the plan also focuses on younger patients and thus addresses the question of whether it is possible for them to carry on working despite the handicap.

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<sup>5</sup> Observatoire 2015 Cap Retraite (2015): *La France face à la prise en charge de la maladie d'Alzheimer. Analyse à l'échelle nationale et départementale*. Available at: [www.data.gouv.fr/s/resources/la-france-face-a-la-prise-en-charge-de-la-maladie-dalzheimer/20150512-092724/etude\\_3\\_-\\_Alzheimer.pdf](http://www.data.gouv.fr/s/resources/la-france-face-a-la-prise-en-charge-de-la-maladie-dalzheimer/20150512-092724/etude_3_-_Alzheimer.pdf).

<sup>6</sup> According to the plan, however, each illness must be seen as having its own particular specifics.

### 2.2.1 Involvement of stakeholders

The strategy is overseen by three professors – Prof. Michel Clanet, Prof. Joël Ankri and Prof. Etienne Hirsch. They are responsible in the name of the French government for implementing the strategy itself as well as ambitious health and research policies.

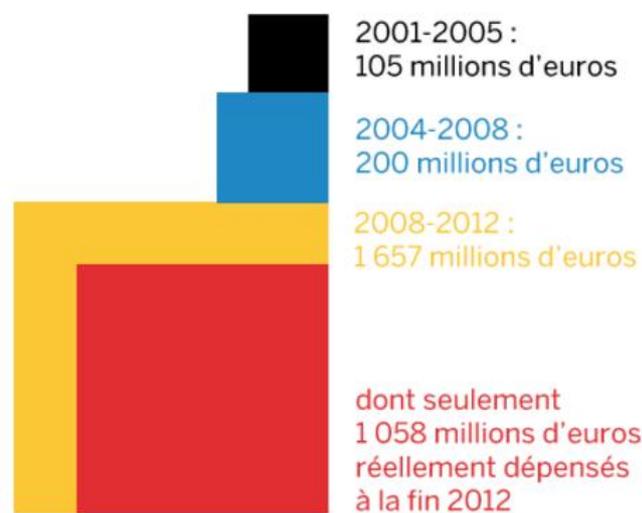
Apart from this directorate, an advisory committee has also been set up. This unites 46 stakeholders and is comprised of the following members: associations, among them self-help organisations (incl. France Alzheimer), medical specialists, representatives of social and health care services, representatives of local authorities, representatives of the research community and partner organisations (incl. Fondation Médéric Alzheimer).<sup>7</sup> Although people suffering from neurodegenerative illnesses are not explicitly listed, they are least represented through the relevant self-help organisations.

The form in which the stakeholders were involved in creating the strategy is not mentioned.

### 2.2.2 Funding

The strategy itself does not contain any precise details of the amount or the source of funding. This vagueness caused the associations to voice their disappointment and dismay in the wake of the publication. According to the president of France Alzheimer, the expectations concerning financing have not been fulfilled. In order to understand the criticism, it is useful to briefly review the first three strategies (see Figure 1).

**Figure 1: Overview of the budgets for the first three strategies**



Source: France Alzheimer, 2013

The budgets for the first two strategies were € 105 million and € 200 million respectively. The third strategy even had a budget of € 1,6 billion, only € 1,058 billion of which had been spent by the end of 2012, leaving € 942 million still to be allocated.

<sup>7</sup> All the stakeholders involved are listed in detail on p. 118f. in Annex 2 of the strategy (2014-2019).

In addition, the third strategy (2008-2012) contained a funding schedule stretching over several pages. It detailed the exact amount of the budget and stated precisely how much was to be allotted to each field and, in some cases, even to specific measures (see 3<sup>rd</sup> strategy p. 7-11).

The expectations the associations had with regard to the funding of the new strategy were therefore high, as it contained an even greater number of specific measures and had additionally been expanded to take in other illnesses.

During a government question time, Minister Marisol Touraine was asked how the strategy was to be funded. Her on-record answer stated that € 470 million was to be provided to implement the strategy over its complete term.

### **2.2.3 Binding nature and monitoring the success of implementation**

The current strategy also foresees an external evaluation that is to accompany the implementation right from the start. The procedure is stipulated in specific measure 89 (see 4<sup>th</sup> strategy p. 110).

The directorate and the advisory committee are responsible for implementing the strategy. Precise procedures for controlling and monitoring implementation are not stated.

### **2.3 Status of implementation**

The strategy describes 96 single measures. Their description is usually kept quite general, no time schedule is stated for their implementation and there is no detailed information about the budget available. However, a direct description of the activity to be implemented is given for some of the measures. Other measures from the previous strategy have been continued or adapted.

### **2.4 Analysed measure: the organisation model "*Method of action for the integration of assistance and care services in the area of autonomy*" (MAIA)**

The care and nursing system in France is broken down into several levels and sectors: on the one hand there are the social and medical sectors in the health service; on the other hand there is the hospital sector including urban health care. Added to this is the differentiation between the private sector, the public sector and the associations and, last but not least, responsibilities are sub-divided at national, regional, departmental and municipal levels. The organisational model described below was created to improve coordination and promote better teamwork so as to overcome this fragmentation.

The scheme *Maisons pour l'autonomie et l'intégration des malades Alzheimer* (MAIA) was created in the strategy running from 2008 to 2012. This is a model to encourage integration and enable a self-determined life for people with Alzheimer's disease. It first ran through a pilot phase and was subsequently evaluated. MAIA centres have existed since 2011 and covered 60% of municipalities by the end of 2013 (i.e. 6 of 10 municipalities had implemented the measure).

The evaluation of the third strategy in 2013 confirmed that it was desirable to continue MAIA. Six recommendations were formulated to further anchor the concept (see the evaluation of the strategy 2008-2012, p. 28).

Single measure 34 in the new strategy has the following aims: *"The efforts and the dynamics of integrating the nursing and support services for older people in need of care are to be continued and strengthened by means of MAIA."*<sup>8</sup>

In the current 2014-2019 strategy, the name *Maisons pour l'autonomie et l'intégration des malades Alzheimer* has been changed to *méthode d'action pour l'intégration des services d'aides et de soins dans le champ de l'autonomie* – thus a plan of action to integrate care and nursing services to foster a self-determined life. Although the scheme was renamed, the abbreviation MAIA and the quality it stands for were retained. The name change is intended to signal that MAIA no longer specialises only in dementia. It is not the scheme itself that has changed, but rather the method of approach. In addition, people had previously been irritated by the term *maison* (house). This seemed to imply that there was a place or point of contact that could be visited, which was not the case.<sup>9</sup> The model has always been a method of co-ordinating all the actors involved and integrating all the services concerned.

MAIA is not an institution, but rather an organisational model with a holistic approach adapted to the local level. The concept is made up of three mechanisms:

1. strategic coordination between the providers of funding and decision-makers (incl. ARS and CARSAT<sup>10</sup>) in order to implement a joint project.
2. central points of contact in which providers of care, nursing and health services (e.g. health care professionals, hospitals, nursing homes, care-at-home providers etc.) interact, work in a uniform manner and align their work to the requirements of those in need of care.
3. specially trained case managers.

MAIA aims to coordinate care and nursing services and create a "virtual" coordination office. A multitude of actors (general practitioners, social services, hospitals etc.) must work together in order to help and support elderly people. The quality of the support and care depends on the degree of coordination and the existing networks.

The following approaches are deployed in MAIA: harmonisation of information; use of the same language; orientation to suitable, high-quality services; the aforesaid networking of stakeholders; shared approaches and procedures; regular meetings between professionals

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<sup>8</sup> Original phrasing from the strategy for 2014-2019; p. 49: *"Poursuivre l'effort et consolider la dynamique d'intégration des services d'aide et de soins pour les personnes âgées en perte d'autonomie grâce au déploiement des dispositifs MAIA."*

<sup>9</sup> There are points of contact in this sense in France with the (declining number of) CLIC geriatric counselling centres (*centre local d'information et de coordination gérontologique*), where people in need of care and their relatives can obtain information and support on the spot or be referred on to specialists. There is a comparable model in Germany with the care support centres established by health and nursing care insurance schemes at the behest of some German states.

<sup>10</sup> ARS (*Agences régionales de santé*) are regional health care agencies. CARSAT (*Caisse d'Assurance Retraite et de la Santé au Travail*) is an insurance scheme for pensions and industrial health care.

(*table tactique*) and between those who make decisions and provide funding (*table stratégique*).

The aims are to provide integrated services for all those in need of care and their families and to call on medical and social services for coordinated, individual care. The model is coordinated by one pilot (*pilote*) per MAIA, who works at the political and operational level and organises regular meetings between the actors involved. At the practical level there are trained case managers (*gestionnaires de cas*).

The case managers attend to people in need of care in complex situations (concerning their surroundings, health or family). They are primarily assigned to deal with difficult cases which are discussed beforehand in the regular meetings.

This model is intended to facilitate access to suitable services, prevent gaps in the care provided and promote a uniform provision of care. Last but not least, it should pinpoint any requirements or gaps in care in a district so that these can be catered for or plugged.

There was a total of 252 MAIA in 2014. The new strategy foresees that a further 100 will be added in the next two years, so that the model can be implemented across the country as quickly as possible (50 in 2015 and another 50 in 2016).

MAIA is mainly financed by the state long-term care insurance scheme (CNSA), by contributions from the regional intervention fund (FIR)<sup>11</sup> and by the regional health care agencies (ARS). The legislative basis is the Social Insurance Finance Act of 2011.

An expert in France reported that many people profit from this model in their work and that it has brought about a tangible improvement in teamwork, even if this claim certainly needs to be differentiated from one MAIA to the next.

### 3 SCOTLAND

Section 3.1 describes Scotland's first national dementia strategy (2010-2013). The framework conditions of the second dementia strategy for the years 2013 to 2016 are depicted in section 3.2, whilst the status of implementation is reviewed in section 3.3. The "*Dementia Nurse Consultants*" and the "*Dementia Champions Programme*" initiatives are analysed in section 3.4 as examples of action to improve dementia care in general hospitals.

#### 3.1 Excursus: Scotland's first national dementia strategy (2010-2013)

Around 90,000 dementia sufferers live in Scotland in 2015, of whom some 3,200 are younger than 65 years of age.

Scotland's first national dementia strategy<sup>12</sup> was published by the Scottish government in 2010. It was scheduled to run for three years and was described in 60 pages. The first strat-

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<sup>11</sup> CNSA = *Caisse Nationale de Solidarité pour l'Autonomie* / FIR = *Fonds d'Intervention Régional*.

<sup>12</sup> The Scottish Government; Healthier Scotland (2010): *Scotland's National Dementia Strategy*. Available at: [www.gov.scot/Resource/Doc/324377/0104420.pdf](http://www.gov.scot/Resource/Doc/324377/0104420.pdf).

egy was presented in a highly attractive manner with numerous colour pictures. The aim was to reach as broad a public as possible. The strategy centred on people with dementia and it named eight actions to support change: 1. develop nursing standards; 2. improve staff skills and knowledge; 3. pilot an integrated change programme; 4. improve information systems; 5. continued improvement of diagnosis; 6. ensure access to appropriate treatment and support; 7. faster implementation of the dementia care pathway; 8. continued support for research into dementia.

The implementation of the strategy was overseen by a monitoring group which met three times a year. The first "*One Year On Report*"<sup>13</sup> was published in June 2011. This reviewed the progress of implementation and described the monitoring process. One of the successes identified in the report was the rise in the rate of diagnosis. In 2007, only a third of all people with dementia received a formal diagnosis. Five years later, in March 2012, Scotland had achieved a diagnosis rate of 64%. At the same date, England had a diagnosis rate of just 44%, whilst Wales had managed to achieve only 38%. Scotland's defined aim for 2015 is to achieve a rate of 67%.

The objectives of the first strategy were kept quite general. Hardly any through-going time-frames for implementing the measures were stated, nor was any financial framework declared.

### 3.2 Framework conditions

The second national dementia strategy (2013-2016)<sup>14</sup> builds upon the first strategy and is likewise set to run for three years. It is laid down in 23 pages of plain text. In contrast to the first strategy, it resembles a work paper, without logos, pictures or graphics.

A total of 17 commitments are to be implemented. It is worth noting that all the commitments start with an active formulation ("we will"), followed by a description of what is to be done.

Feedback from the National Dementia Dialogue has been taken up and included in the second strategy, such as the call for a digital platform to give people with dementia and their families easier access to information and enable them to regard themselves as equal partners in the care process (see commitment 9).

The primary goal of the strategy is to bring about a "real" improvement for people with dementia here and now.

#### 3.2.1 Involvement of stakeholders

Some background information from the first national dementia strategy is useful in order to understand how stakeholders were involved in the second strategy. Five so-called work-streams were formed at that time to examine five different areas concerned with dementia. In

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<sup>13</sup> The Scottish Government; Healthier Scotland (2011): *Scotland's National Dementia Strategy: One Year On Report*. Available at: [www.gov.scot/resource/doc/350341/0117259.pdf](http://www.gov.scot/resource/doc/350341/0117259.pdf).

<sup>14</sup> The Scottish Government; Healthier Scotland (2013): *Scotland's National Dementia Strategy: 2013-2016*. Available at: [www.gov.scot/Resource/0042/00423472.pdf](http://www.gov.scot/Resource/0042/00423472.pdf).

total, 41 organisations participated in the workstreams. These included the *Dementia Services Development Centre*, *Alzheimer Scotland*, the *Scottish Dementia Working Group* and *Stirling University*, to name just a few. Each workstream prepared a report with detailed recommendations on how to develop a strategy. These reports then served as a basis for consultation and dialogue with a wide range of stakeholders. The consultation paper was published in 2009. Organisations and individuals could submit their comments and respond to specific questions.

The second strategy was developed – in exactly the same way as the first – on the basis of participation and dialogue. Among other things, the National Dementia Dialogue is to be set forth in conjunction with Alzheimer Scotland. In February 2013, the Scottish government published a written proposal paper to further refine the second strategy from the consensus of recommendations that had emerged from this dialogue. This proposed the content and measures that were to form the basis of the strategy. The paper was sent to participants in the dementia dialogue for their comments before being subsequently finalised as the second strategy by an expert group.

The involvement of the *Scottish Dementia Working Group*, which is run by people with dementia, meant that the views and experiences of people with dementia, their families and carers could be taken into account.

### 3.2.2 Funding

There is no reference to direct funding from the Scottish government in the national strategy.

The sole reference to funding in the strategy is found in commitment 15 (see p. 20), in which the government promises to continue funding the research work of the *Scottish Dementia Clinical Research Network*.<sup>15</sup> However, the level of funding is not stated.

Specific measures are funded by the *Big Lottery Fund*, a UK organisation which distributes funds for good causes concerned with improving health, education and the environment (comparable to *Aktion Mensch* in Germany). One recipient is the *Life Changes Trust*, an independent Scottish charity established in April 2013 with a £ 50 million endowment from the *Big Lottery Fund*, which is to be distributed over ten years. The trust was created "to drive real and meaningful improvement in the lives of young people with experience of being in care and people affected by dementia".

### 3.2.3 Binding nature and monitoring the success of implementation

The implementation of the strategy is overseen by a monitoring group that meets three or four times a year and publishes an annual report. It is headed by the Scottish government and includes major stakeholders in the strategy, various service providers, including volun-

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<sup>15</sup> The *Dementia Clinical Research Network* was established by the government in August 2008 with a grant of £ 1 million. Funding was extended up to 2014. One thing that the Dementia Clinical Research Network, working together with Alzheimer Scotland, offers to people with dementia and their carers is the chance to participate in studies in the early stages of the illness with potential opportunities for treatment.

tary organisations, social service providers and representatives from the legislature, Alzheimer Scotland and people with dementia and their carers.

The monitoring group is an additional national structure that had already been deployed in the first strategy. Its remit is to ensure coordination, support and progress in implementing the strategy's 17 commitments as a whole and some of the sub-steps.

Monitoring includes identifying changes and improvements made in dementia services over the course of time. It uses a benchmark analysis which draws on available sources of data, wherever feasible, or on data derived from the analysis. Account is taken of the following items in the analysis:

- number of people with diagnoses
- number of people who receive support and information after diagnosis
- reduction in unnecessary hospital admissions
- reduction in prescriptions of psychotropic drugs
- compliance with laws concerning people with handicaps
- expansion of social, communal and physical activities
- improvement in levels of experience and in dealing with people with dementia and their carers

The minutes of the regular meetings can be called-up from the Scottish government's web site. The monitoring group additionally publishes a report in June each year.

A meeting of the commission is planned for June 2016. This will allow experiences to be exchanged and the learning process to be discussed in consideration of and with regard to the development of a follow-up strategy.

The Dementia Forum is also continuing its work in the second strategy as a platform for a broad network of stakeholders and affected people to discuss the process of implementing the strategy. The forum is chaired by the Minister of Public Health.

### **3.3 Status of implementation**

The 17 commitments particularly include two key issues that were already named in the first strategy and have been continued in the second strategy: 1) the focus on early diagnosis and providing information and support to people with dementia after diagnosis; 2) improvement of care services for people with dementia in general hospitals.

Timely diagnosis (thus raising the rate of diagnosis even further) is a key component because access to care structures first requires a diagnosis. Only then can those affected be given advice and support, start to receive treatment at an early stage and generally start to

come to terms with the changes.<sup>16</sup> A national 10-point plan of action<sup>17</sup> (see p. 15 of the strategy) was developed to improve the care and nursing of people with dementia in hospitals and to establish standards of care. The plan of action is set to run for three years. The development of the plan of action is laid down in commitment 10 of the strategy – *"We will develop and deliver a 3-year National Action Plan to improve care in acute general hospitals."* A national consultation process involving all NHS main boards<sup>18</sup> was launched in March 2015 to discuss all ten actions in the plan.

### 3.4 Analysed measures: *"Dementia Nurse Consultants"* and *"Dementia Champions"*

The uniform standards of care for dementia that were developed in the first strategy, based on the Charter of Rights for People with Dementia, state individual rights. One of these rights is: *"I have the right to have carers who are well supported and educated about dementia."*

In order to comply with this right by providing nursing staff properly trained in treating people with dementia, the Scottish government determined in the second strategy that the NHS boards<sup>19</sup> should be supported in the process of change and that two initiatives should be further expanded: *"Dementia Nurse Consultants"*, run by Alzheimer Scotland, and *"Dementia Champions"*. Patients with a secondary diagnosis of dementia are a particular challenge for the generally tightly synchronised nursing procedures in hospitals and for the staff working there. If the process fails, it can have serious consequences for these patients, for instance delirium. Scotland has already developed a number of showpiece models for the design of dementia-friendly departments in hospitals. An example is the "virtual hospital"<sup>20</sup> developed by the *Dementia Services Development Centre (DSDC)*<sup>21</sup> in Stirling. This dementia-friendly hospital is modelled using simple design principles, such as extra lighting and red<sup>22</sup> toilet

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<sup>16</sup> The Scottish government, in collaboration with Alzheimer Scotland, has introduced a *5 Pillar Model of Post Diagnostic Support* to support people after their diagnosis. Under this model, every person in Scotland who is newly diagnosed as having dementia is entitled to one year of post-diagnostic support. During this 12-month period, they have the right to have a personal plan prepared with the help of a specially trained link worker, which is based on the 5 pillars. Further information on this model can be found in our newsletter *"National dementia strategies: Examples of good practice in Switzerland and Scotland"*. The newsletter issued by the Observatory for Sociopolitical Developments in Europe, Merkle, Maike, 09/2015, is available at: [http://www.sociopolitical-observatory.eu/uploads/tx\\_aebgppublications/Demenz\\_NL\\_Engl\\_01.pdf](http://www.sociopolitical-observatory.eu/uploads/tx_aebgppublications/Demenz_NL_Engl_01.pdf).

<sup>17</sup> The ten points of the plan are: 1. *Identify a leadership structure within NHS Boards to drive and monitor improvements* 2. *Develop the workforce against the Promoting Excellence KSF* 3. *Plan and prepare for admission and discharge* 4. *Develop and embed person-centred assessment and care planning* 5. *Promote a rights-based and anti-discriminatory culture* 6. *Develop a safe and therapeutic environment* 7. *Use evidence-based screening and assessment tools for diagnosis* 8. *Work as equal partners with families, friends and carers* 9. *Minimise and respond appropriately to stress and distress* 10. *Evidence the impact of changes against patient experience and outcomes.*

<sup>18</sup> NHS stands for the *"National Health Service"*. NHS Scotland is the publicly financed health system in Scotland. Health and social policies and funding are the responsibility of the Scottish Health and Social Care Directorates.

<sup>19</sup> The NHS is made up of 14 regional *NHS Boards*. These are responsible for safeguarding and improving the health of the population and for providing health services. Seven specialised *NHS Boards* support the general *NHS Boards* by providing a series of specialists and further domestic services.

<sup>20</sup> The virtual hospital web site is available at <http://dementia.stir.ac.uk/design/virtual-environments/virtual-hospital>

<sup>21</sup> The DSDC is an international centre of knowledge and expertise for improving the quality of life for people with dementia. The centre is affiliated to the University of Stirling in Scotland.

<sup>22</sup> Experts believe that the colour "red" is perceived longer by people with dementia than other colours.

seats and cups. A measure aimed at improving the care of dementia sufferers in hospitals is the "*Dementia Champion Programme*", which is now described below.

Among other things, the two initiatives "*Dementia Nurse Consultants*" and "*Dementia Champions*" refer to commitment 11 in the second dementia strategy: "*We will set out plans for extending the work on the quality of care in general hospitals to other hospitals and NHS settings.*"

The national plan of action (see second strategy p. 15f.) was developed to provide good, effective care in hospitals for people with dementia.

Alzheimer Scotland introduced the *Dementia Nurse Consultant* programme in 2006. Four consultants in four regions were initially appointed for a period of four years. Working together with Alzheimer Scotland, the Scottish government is currently sponsoring specially trained dementia nurse consultants in all 14 NHS boards. Thus each region now has a strategic manager responsible for bringing about the improvement in care that is strived for.

*Dementia Champions* is a nationwide programme that was launched in 2011. It aims to provide special training for nurses in order to prepare them to spearhead the change towards more dementia-friendly care in their hospitals by giving them a say in decision-making. The idea behind the programme is that these trained staff are proud of their title, and this helps build a new culture of caring. Moreover, this change is not imposed "top-down", but rather works as a "bottom-up" approach. Most *Dementia Champions* are nurses or persons working in related health professions.<sup>23</sup>

The programme aims to support the *Dementia Champions* as *Change Agents* in order to improve the care and support available to people with dementia and their families in general hospitals and at the interface between hospitals and social services at municipal level.

These two initiatives make up a two-pronged concept and are closely interlinked. The *Dementia Nurse Consultants* are envisaged as directors and strategic managers for the *Dementia Champions*, who in turn act as *Change Agents* to bring about change on the ground. One of the potential benefits is networking within the various disciplines (nurses, social workers and health care professionals). Evaluation has shown (see below) that the better the teamwork, the greater the improvement in the care and support given to people with dementia and their families. However, this collaboration is not laid down in formal terms.

The special training given to nursing staff is intended to drive the change towards dementia-friendly hospitals and improve care and the way in which people with dementia are treated. The extra-occupational training is arranged by *NHS Education for Scotland* (NES). The one-year course was prepared by the *University of the West of Scotland* together with Alzheimer Scotland on behalf of NES.

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<sup>23</sup> Apart from the (*Health*) *Dementia Champions* who work in hospitals, there are also some *Social Services Dementia Champions* who are deployed in the field of social services.

500 health care professionals are currently undergoing training as *Dementia Champions* in Scotland. A sixth cohort started in April 2015. This means that some 600 trained *Dementia Champions* can be expected by 2015/2016.

The impact and effectiveness of Alzheimer Scotland's *Dementia Nurse* initiative and the *Dementia Champions* initiative were evaluated at the behest of *NHS Education for Scotland*. The evaluation report<sup>24</sup> published in 2014 confirmed the positive impact on the intended change in care and identified a great number of changes and improvements in dementia care in hospitals. The authors of the evaluation study believe these would probably not have come about without these initiatives.

One of the improvements attributable to the initiatives is that patients older than 65 years of age are examined for dementia when they are admitted into a hospital. This examination takes the form of four questions. A "Getting to Know Me"<sup>25</sup> questionnaire can be completed by the patients or their relatives. This gives information about the patient with dementia to ensure that he or she gets the best possible care. The idea behind this is that all people with dementia are individuals with their own likes and dislikes. If someone is to receive good care, it is an immense advantage to know something about them. The trained staff take time with the communication process and pass their knowledge on to colleagues. For example, signs with images and titles were stuck to doors. There are dementia boxes with materials from past times to look at, remember and touch.

The initiatives are financed by the Scottish government and Alzheimer Scotland.

## 4 SWITZERLAND

The introduction to this section describes the situation of people with dementia in Switzerland and how the first Swiss dementia strategy came about (4.1). Section 4.2 reviews the framework conditions and fields of action in the Swiss dementia strategy. Section 4.3 depicts the status of implementation, which is followed in section 4.4 by the analysis of a project to provide information and raise awareness.

### 4.1 Excursus: pathway to the Swiss dementia strategy

It is estimated that around 110,000 people with dementia live in Switzerland at the present time, and that 28,000 new cases are added each year. The number may well triple by 2050. Switzerland has reacted to this challenge by putting together a national dementia strategy.

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<sup>24</sup> Ellison, S.; Watt, G.; Christie, I. (2014): "Evaluating the impact of the Alzheimer Scotland Dementia Nurse Consultants/Specialists & Dementia Champions in bringing about improvements to dementia care in acute general hospitals", NHS Education for Scotland. Available at: [www.nes.scot.nhs.uk/media/2711493/impact\\_evaluation\\_-\\_final\\_report.pdf](http://www.nes.scot.nhs.uk/media/2711493/impact_evaluation_-_final_report.pdf).

<sup>25</sup> Alzheimer Scotland and The Scottish Government (2013): *Getting to Know Me*. Available at: [www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/4061922/037\\_280\\_gettingtoknowme\\_1369954145.pdf](http://www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/4061922/037_280_gettingtoknowme_1369954145.pdf).

The impetus to develop a national dementia strategy came from two motions<sup>26</sup> (Steiert motion and Wehrli motion), which were submitted to the National Council in 2009 and passed on to the Swiss Federal Council in March 2012. The control and fulfilment of the remit was embedded in the *"Dialogue on national health policy"*, a joint platform of the federal government and the cantons. The job of elaborating the motions was given to the Federal Office of Health (BAG) and to the Swiss Conference of Health Directors of the Cantons (GDK).

BAG and GDK then commissioned Ecoplan AG, a company specialising in research and consultancy services for business and politics, with the task of preparing the *"basis for a national dementia strategy in Switzerland: initial situation"*, which was published in 2013.<sup>27</sup> The aims of this basis report were to describe the current situation in Switzerland and to bundle the knowledge of experts in order to identify the need for action and to formulate recommendations for such action.

GDK furthermore reviewed the situation in the cantons (2013)<sup>28</sup> in order to identify the dementia care services already existing in Switzerland, to establish priorities for the action required and to formulate what was expected of the Swiss strategy.

From the view of the cantons, two strategies can be named that were already in place: Waadt canton published the *"Alzheimer and related illnesses"* programme back in 2010, and Wallis canton followed in 2011 with a strategy entitled *"People with dementia – the situation in Wallis – recommendations"*. Other cantons already had a dementia policy. When asked if they were interested in a national dementia strategy, all 26 cantons expressed an interest in information on continuous developments.

### 4.2 Framework conditions

The Swiss National Dementia Strategy 2014-2017<sup>29</sup> was published on 21 November 2013. It is broken down into four fields of action:

1. health expertise, information and participation (with the focus on society)
2. services tailored to requirements (with the focus on care)
3. quality and specialist skills (with the focus on professional expertise)
4. data and passing on knowledge (with the focus on research → practice)

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<sup>26</sup> A motion is an application made in the Swiss parliament asking the Federal Council to present a draft decree or to pass a resolution.

<sup>27</sup> Ecoplan (2013): *Grundlagen für eine Nationale Demenzstrategie. Demenz in der Schweiz: Ausgangslage*. Federal Office of Health (BAG) / Swiss Conference of the Health Directors of the Cantons (GDK). Available at: [www.bag.admin.ch/themen/gesundheitspolitik/13916/](http://www.bag.admin.ch/themen/gesundheitspolitik/13916/).

<sup>28</sup> Coppex, P.; Wyss, N.; Central Secretariat of the GDK (2013): *Bestandsaufnahme der Demenzversorgung in den Kantonen. Bericht über die Resultate der Umfrage in den Kantonen (January-April 2014)*. Available at: [www.gdk-cds.ch/fileadmin/docs/public/gdk/themen/strategie\\_bundkantone/demenz/bt\\_demenzversorgung\\_d\\_2013.11.21.pdf](http://www.gdk-cds.ch/fileadmin/docs/public/gdk/themen/strategie_bundkantone/demenz/bt_demenzversorgung_d_2013.11.21.pdf).

<sup>29</sup> Federal Office of Health (BAG) and Swiss Conference of the Health Directors of the Cantons (GDK) (2013): *National Dementia Strategy 2014-2017*. Available at: [www.bag.admin.ch/themen/gesundheitspolitik/13916/](http://www.bag.admin.ch/themen/gesundheitspolitik/13916/).

A total of nine objectives and 18 projects are assigned to these four fields of action. The objectives aim to improve the quality of life of patients, to reduce stress and distress and to warrant the quality of care.

The strategy is described in 40 pages and is available in German, French and Italian. There is also an abridged version available in English.<sup>30</sup>

The strategy is targeted at a wide range of people; because of this, the publication has an appealing design with illustrations and a title page intended to draw the interest of a broad public.

In line with the overarching objectives and values, "*the focus is on people with dementia and those accompanying them in their everyday lives.*" People with dementia should be cared for and supported and the quality of their lives enhanced in consideration of their individual circumstances (e.g. accompanying illnesses, family situation etc.) (see National Dementia Strategy 2014-2017, p. 5).

Another core element of the strategy is to raise general awareness. The aims are to break down stigmas and to promote respect in dealing with people with dementia (see section 4.4).

The limits of the strategy are also stated – the purpose of the dementia strategy is not to completely depict and treat dementia as an illness, but rather to "*reflect the priorities in the need for action in central issues of dementia care*" (see National Dementia Strategy 2014-2017, p. 19).

### 4.2.1 Involvement of stakeholders

The goal in Switzerland was to develop a sustainable strategy oriented to practice. A wide range of stakeholders was involved to achieve this purpose. An initial proposal for the fields of action, objectives and projects was prepared from the preliminary work undertaken in the review of the situation, from an expert report and from further insights into the need for action. These were then validated and refined in a three-stage consultation process. The first round of validation involved an extended consultancy board. In the second round – a hearing – 70 specialists drawn from research, associations, organisations and service providers were consulted. A wide-ranging online consultation was undertaken in a third round.

The following stakeholders were consulted and involved in creating the final strategy: representatives of patient and carer organisations, experts drawn from professional groups and specialist organisations, and those actively working at government, canton and municipal levels.

The coordination of a variety of stakeholders at different levels points to an interdisciplinary approach and to the inclusion of multi-dimensional viewpoints. An interdisciplinary alignment and networking with multiple perspectives is thus strived for. At a horizontal level, stake-

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<sup>30</sup> Summary of the national dementia strategy in English available at:  
[http://www.bag.admin.ch/themen/gesundheitspolitik/13916/index.html?lang=en&download=NHZLpZeg7t,Inp6I0NTU042I2Z6In1ad1IZn4Z2qZpnO2Yuuq2Z6gpJCMdYN3fWym162epYbg2c\\_JjKbNoKSn6A--](http://www.bag.admin.ch/themen/gesundheitspolitik/13916/index.html?lang=en&download=NHZLpZeg7t,Inp6I0NTU042I2Z6In1ad1IZn4Z2qZpnO2Yuuq2Z6gpJCMdYN3fWym162epYbg2c_JjKbNoKSn6A--).

holders from various disciplines are intended to work together; at a vertical level, the team-work cuts through different political and social levels.

#### 4.2.2 Funding

The federal approach adopted in the distribution of tasks between the federal government, the cantons and the municipalities also applies to how the strategy is funded.

The 18 projects envisaged by the strategy for practical implementation are to be initiated de-centrally, i.e. an individual stakeholder (federal government, cantons, specialist associations, patient organisations etc.) which assumes the management of a project must arrange for its funding and personnel. There is no central funding from the Swiss government.

#### 4.2.3 Binding nature and monitoring the success of implementation

Boards and committees have been appointed to implement the strategy in a binding manner, for instance in order to monitor its success.

The federal government (BAG) and the cantons (GDK) administer and coordinate the processes (coordination board), support quality assurance ("National Dementia Strategy 2014-2017" platform) and anchor the objectives in the umbrella associations of the service providers (consultative committee):

- The **coordination board** consists of representatives of the federal government and the cantons. Apart from its coordinating role, the board also heads the consultative committee and the platform. It is also responsible for reporting regularly on the implementation status of the strategy on behalf of the "National Health Policy Dialogue".<sup>31</sup>
- The **consultative committee** is composed of representatives of patient organisations, professional and specialist associations, the umbrella associations of the service providers and stakeholders drawn from education and research. The job of the consultative committee is to anchor the dementia strategy in the umbrella associations and professional organisations.
- The **"National Dementia Strategy 2014-2017" platform** is a board that unites all those who manage the projects in the course of implementing the strategy. The platform is intended to document, oversee and evaluate the progress made in implementing each of these projects.

#### 4.3 Status of implementation

The majority of the projects are models that have proved to be "good practice" in providing dementia care. These are now to be further developed, expanded, coordinated and overseen at national level.

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<sup>31</sup> The "National Health Policy Dialogue" is the standing platform of the federal government and the cantons. It provides both partners in the dialogue with the opportunity to discuss issues and tasks of health policy and to make the necessary agreements. The dialogue is expanded in some issues to take in other major stakeholders in health services in order to deal with strategic questions of national health policy.

The principles underlying the Swiss strategy are to initiate the projects decentrally but to coordinate them at national level. The government and the cantons are responsible for the process and its coordination, as is fitting for the federal approach taken in the distribution of tasks. Each specific project is managed by a so-called project leader. This project leader is responsible for organising the personnel and financial resources required for the stand-alone project and for reporting on its progress.

A project is implemented in a rolling, staggered process. This creates project interplays within the strategy and establishes interactions with projects in the overall setting of the strategy. As at February 2015, seven of the 18 projects were being managed by project leaders responsible for the implementation and funding of the individual project. Further project leaderships are still being negotiated.

#### **4.4 Analysed measure: providing information and raising awareness**

The Swiss government, the cantons and various stakeholders launched the first five projects in the "Dementia Strategy 2014-2017" at a meeting in Berne in May 2014. One of these projects, which is concerned with raising social awareness of dementia and is currently being implemented, is presented and analysed below.

The project is assigned to the first objective of the Swiss dementia strategy. The intention is to inform, to raise awareness and to mobilise the general public on the issue of dementia in the best possible way. It is known from research that it is essential to involve the public at large in order to promote acceptance and come to terms with the issue of dementia and to encourage respect in dealings with the people with dementia themselves. Prejudices and inhibitions amongst the general public towards people with dementia must be overcome as much as possible. Project 1.1 "Providing information and raising awareness amongst the public and in the communities" is described as follows: *"The content of the information should take account of the realities of the daily lives of the different target groups and the variety of support services on offer. Information should furthermore promote solidarity and integration. People with dementia should be involved as stakeholders"* (see National Dementia Strategy 2014-2017, p. 21).

The project is overseen by the Swiss Alzheimer's Association and Pro Senectute Switzerland.<sup>32</sup>

An initial campaign to raise awareness (entitled "*Dementia can affect anyone*") was launched at the end of May 2015 as the first phase of the project. It is an online campaign centred on the website "*www.memo-info.ch*" (available in three languages). The campaign combines posters, adverts in print media and online promotions calling on the public to visit the website to find out about dementia, the warning signs, preventative action and the different therapies available, as well as to test their knowledge. The content of the web campaign is easy to un-

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<sup>32</sup> Pro Senectute is the largest professional service provision organisation for the elderly in Switzerland. It provides free advice and support to senior citizens in over 130 advisory centres throughout Switzerland.

derstand. People with dementia are also involved, as the website includes reports and interviews about their experiences.

The campaign revolves around the idea of forgetfulness and memory gaps. It presents situations to viewers that they may recognise from everyday life and highlights these as potential signs of dementia. Messages on yellow Post-It notes broach the issue in visual terms: *"Forgotten someone's name again?; Still trying to find the car?; Missed yet another appointment?; Can't remember that code at all?"* Viewers feel that they are being addressed because they recognise the situation. Although a certain forgetfulness goes hand in hand with growing old, such symptoms should not occur with excessive frequency. Although reasons for forgetting things may vary, viewers are nevertheless encouraged to reflect more deeply about forgetfulness.



Two Post-It notes as examples from the "Dementia can affect anyone" campaign. Source: [www.memo-info.ch](http://www.memo-info.ch).

A second wave in the poster campaign is planned to start in November 2015. Promotional notices are to be placed in print media and online on a continuous and regular basis.

A multiplier campaign is also planned to ensure that the campaign is widespread and reaches as many people as possible. The intention is to encourage participation not only at national level, but also in the cantons and municipalities. This task is to be taken on in particular by the cantonal representations of the Swiss Alzheimer Association. However, doctors' surgeries, pharmacies, hospitals, educational institutions, senior citizens' homes and other local partners will be given free materials (such as posters and flyers) to hang up or display, so that they, too, can function as multipliers.

The aims of the campaign are to raise awareness of the social relevance of dementia, spread knowledge about them, remove taboos and stigmas, raise the rate of early recognition and diagnosis and create an understanding of the situation that patients and their relatives find themselves in. Dementia is thus to remain in the public eye.

The Swiss Alzheimer Association initially estimated a resource requirement of 2 million Swiss Francs for 2014 and 2015. The campaign is financed by the Swiss Alzheimer Association and Pro Senectute on a 50/50 basis.

As a first step, an initial survey<sup>33</sup> was conducted to enable the impact that this traditional, long-term campaign has had in raising public awareness to be gauged. The dementia ba-

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<sup>33</sup> The Swiss Alzheimer Association commissioned GFS-Zürich Markt- und Sozialforschung to conduct this survey.

rometer<sup>34</sup> questionnaire was reduced for this purpose and adapted to the goals of the campaign. Some 1,000 people were then questioned in May 2015. The survey is to be repeated in two years' time, so that it should be possible to ascertain whether attitudes and behaviour really have changed in the meantime.

## 5 SUMMARY & COMPARISON

The progress made in implementing the strategies in each of the countries is summarised below on the basis of the selected analysis criteria and compared to each other. On the basis of each country's results, similarities and differences in implementation are analysed and favourable and detrimental factors identified.

### 5.1 Comparison of the fields of action

The contents of the fields of action stated at the beginning of this working paper (see p. 2), which were derived from secondary research, can be found in all three national dementia strategies that have been analysed here. There are therefore no great differences in the content covered by the three strategies. Sometimes content is listed in the form of a field of action or sometimes as objectives in specific measures.

Alzheimer's Disease International (ADI) has recommended that national dementia strategies should cover the following ten issues (see Bupa/ADI Report 2013, p. 17).<sup>35</sup>

1. improve awareness and education
2. improve (early) diagnosis and treatment
3. improve support available at home
4. strengthen support available to family care-givers
5. improve residential / institutional care
6. better integrate care pathways and the coordination of care
7. improve training for health care professionals
8. monitor progress
9. commitment to research
10. recognise the role of innovative technologies

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<sup>34</sup> The dementia barometer is a representative poll performed throughout Switzerland to record attitudes, opinions and knowledge of dementia amongst the general public. The poll served as a precursor for the development of Switzerland's dementia strategy and delivered insights for approaches to develop future social campaigns aimed at providing information and raising awareness. A detailed description of the dementia barometer can be requested from the author of the work paper as a long version (only in German). The findings of the dementia barometer are published in a concluding report: Moor, C., Peng, A. & Schelling, H.R. (2013). *Demenzbarometer 2012 Wissen, Einstellungen und Erfahrungen in der Schweiz*.

<sup>35</sup> Pot, A. M.; Petrea, I. (2013): *Improving dementia care worldwide: Ideas and advice on developing and implementing a National Dementia Plan*. Alzheimer's Disease International & BUPA, 2013. Available at: [www.alz.co.uk/sites/default/files/pdfs/global-dementia-plan-report-ENGLISH.pdf](http://www.alz.co.uk/sites/default/files/pdfs/global-dementia-plan-report-ENGLISH.pdf).

The strategies analysed in this paper cover the content of virtually all ten recommendations; just the fifth recommendation seems to have been taken up rather less frequently. This is perhaps because the focus is rather on care-at-home services, on enabling people with dementia to remain in their own homes for as long as possible and on improving care services in general hospitals. It is noticeable that training of volunteers is not even mentioned in the ADI list. However, it can be assumed that civic engagement will become ever more important in future, if new opportunities are to be offered to affected persons to arrange their everyday lives.

### 5.2 Criteria in comparison

The dementia strategies of each of the three countries analysed were investigated using the comparative criteria determined at the start of this paper: scope, presentation and layout, involvement of stakeholders, funding, the binding nature of implementation and how success is monitored. The results of the analysis are now summarised and compared in order to identify similarities and differences.

#### *Scope, presentation and layout*

The media presentation varies from country to country and there are also differences in how a country presents its first and subsequent strategies. At over 100 pages long, the current French strategy is the most comprehensive of those analysed. Although the cover is elaborately designed in colour with logos, the strategy itself does not contain any illustrations or photos. Whilst Scotland's first strategy was quite lavishly presented with appealing pictures of older people, the second rather resembles a neutral working paper without logos, pictures or cover. The Swiss strategy has a graphically appealing layout with a cover, photos, illustrations and colour features.

Any assumption that a particular presentation aims to address the strategy's target groups can therefore not be confirmed. For example, whilst Scotland's second strategy has the most down-to-earth layout, it is addressed not only at experts, but also at a broader public.

#### *Involvement of stakeholders*

In France, an advisory committee uniting a variety of stakeholders was established alongside the directorate. A broad consultation of stakeholders was conducted both in the development of France's third dementia strategy and in its extensive evaluation. Although the form of participation is not described in the current strategy, one expert believes that it was not as extensive as was the case for the third strategy. People with dementia are not explicitly mentioned. Switzerland undertook a wide-ranging, three-stage process of participation which covered multiple levels, perspectives and professions. The range of stakeholders involved in Scotland was likewise broad. Recommendations were put forward on the basis of participation and discussion in the National Dementia Dialogue and were then taken up in the new strategy. Those participating in the dementia dialogue could therefore have a say before the strategy was subject to final revision by a group of experts. It can thus be established that there was broad consultation with the stakeholders in the development of the strategies in all three countries, even though this was less extensive in the case of France's fourth strategy.

The involvement of a wide range of stakeholders is a good basis for achieving acceptance of a strategy and for rallying support for its objectives. As in Scotland, individual patients or groups of patients should be involved, and their needs and wishes taken into account. ADI believes that it is vital that people with dementia and their relatives are involved in and become committed to every dementia strategy. Such groups of people should participate right from the development phase, so that the health and social system can be made more user-friendly, more accessible and easier to accept for everyone concerned. The ADI likewise regards the involvement of representatives of all main interest groups in the development and implementation of a strategy as essential in order to take in all the different sectors and backgrounds and to ensure that all areas of care and support are adequately covered.

### *Funding the strategy*

The French strategies are funded by the state. Its current strategy is financed to the tune of € 470 million. However, this figure was cited without stating where it was to come from and without any precise allocation to the different measures. Compared to the preceding strategies, the expectations of the associations were only partly fulfilled, perhaps because a considerably larger budget had been provided for the third strategy. The strategy in Switzerland is organised along federal lines, although the Swiss government does not provide any central funding. Scotland likewise does not provide central funding for its strategy.

In order to provide continuous care, cover immediate requirements, ensure implementation and work with an eye to the future, funding nevertheless needs to be clearly regulated. ADI recommends reasonable, on-going, obligatory funding to at least cover the following three components: prevention and early recognition; funding of health and social services; finances for monitoring and evaluation (which includes funding of innovation and research aimed at improving the standards of care).

### *Binding nature and monitoring success of the implementation*

The French strategy once again foresees an evaluation. No further procedures for overseeing and controlling its implementation are stated. The binding nature of the Swiss strategy is high due to the obligatory establishment of a coordination board, a consultative committee and a platform to document and evaluate the progress of implementation. The implementation of the Scottish strategy is controlled by a monitoring group. This meets on a regular basis and publishes an annual report on the current status of implementation. The group consists of representatives of the Scottish government, a variety of stakeholders in the strategy, as well as people with dementia and their relatives. In addition, the Dementia Forum is a wide-ranging network of patients and stakeholders that exchanges views on the progress of implementation.

According to ADI, processes of evaluation and monitoring play a key role. Process monitoring should not only record data on prevalence, incidence and fatality rates, but also data concerning the quality of the lives of people with dementia and their (care-giving) relatives, the quality of treatment (whether care at home or in other surroundings) and social integration.

*Status of implementation*

The current French strategy describes a total of 96 specific measures. The description of the specific measures is mostly kept quite general and there is no time schedule set for their implementation. Some measures do describe action to be implemented, whilst others have been derived from the foregoing strategy or adapted from this. The Swiss strategy outlines 18 projects to be initiated decentrally and coordinated at national level. Some actors who are prepared to oversee the implementation and arrange the funding of the projects have been appointed, whilst others are still being sought. Most of the projects have proved to be "good practice". The Scottish strategy lays down 17 commitments to be tackled and implemented. These contain two particular focal points.

ADI identified the following factors as having positive effects on the implementation of a national dementia plan (see Bupa/ADI Report 2013, p. 25):

- recognition of dementia as a public health priority
- leadership at a national level
- people engagement (to develop and implement a strategy)
- involvement of all key stakeholders
- introducing a "system of care" and a "case management" approach
- committing funding
- effective monitoring, evaluation and update

## 6 CONCLUSIONS FOR GERMANY

The following findings established from research and analyses can be noted as relevant for the situation in Germany:

The comparison has shown that there is no such thing as a model strategy. The approaches differ and the development of a strategy depends on a range of national factors.

The main priority of a dementia strategy should be to improve the quality of life of the people with dementia and their relatives. Further factors – such as clear responsibilities, in particular a national leadership, a properly allocated budget, a time schedule, a coordinated procedure, a stipulation of the measures to be taken (such as plugging gaps in the system of care), the involvement of people with dementia and a multitude of stakeholders through to better informing the general public – would appear to be conducive in a high quality, targeted strategy, or at least assist its development.

The comparison of the three strategies makes clear that an excellent foundation has been laid in the *Allianz für Menschen mit Demenz*. The fields of action undertaken by this alliance (science and research, social responsibility, support for people with dementia and their families, proper arrangement of the system of care and support) already cover the majority of the fields of action recommended for a dementia strategy.

A variety of measures have already been tried in practice and received financial support under the local alliances (Lokale Allianzen für Menschen mit Demenz) as an initiative of the Federal Ministry of Family Affairs, Senior Citizens, Women and Youth (BMFSFJ). The local alliances have also been networked, for instance by regular meetings at national level to exchange experiences. In addition, an evaluation of the local alliances is foreseen in order to measure their effectiveness.

The alliance has already brought together around one table a multitude of external and internal stakeholders (i.a. the federal government, the states, municipalities, civil society and self-help organisations), thereby creating a good framework for further concerted action. The inter-ministerial responsibility of the alliance under the lead of the Federal Ministry of Family Affairs, Senior Citizens, Women and Youth and the Federal Ministry of Health (BMG) has created a leadership at national level. This is likewise one of the criteria stated by ADI that has already been fulfilled.

Key elements of the factors stated at the outset as being purposeful are thus already in place and should either be taken up in the strategy or further developed. The other main items to be worked on in future to ensure successful implementation particularly include the involvement of a wide range of stakeholders, comprehensive funding for the strategy and a well thought-out process of evaluation.

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