



Carers' perspectives

Paris – 6 May 2009

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Agenda

- **Alzheimer Europe**
- **Carers' Survey Findings**
 - Behavioural problems experienced by carers
 - Availability and use of services
 - Disclosure of diagnosis and information needs
- **European Collaboration on Dementia**



Alzheimer Europe

- **Members**
 - 31 national Alzheimer associations in 27 European countries
- **Mission statement**
 - Changing perceptions, policy and practice in order to improve the access by people with dementia and their carers to treatment options and care services

Key challenges

- **6.1 million people with dementia in European Union**
- **Socio-economic impact of the disease**
- **Late diagnosis**
- **Impact on carers**
- **Lack of services**
- **Differences across Europe with regard to access to treatment and services**

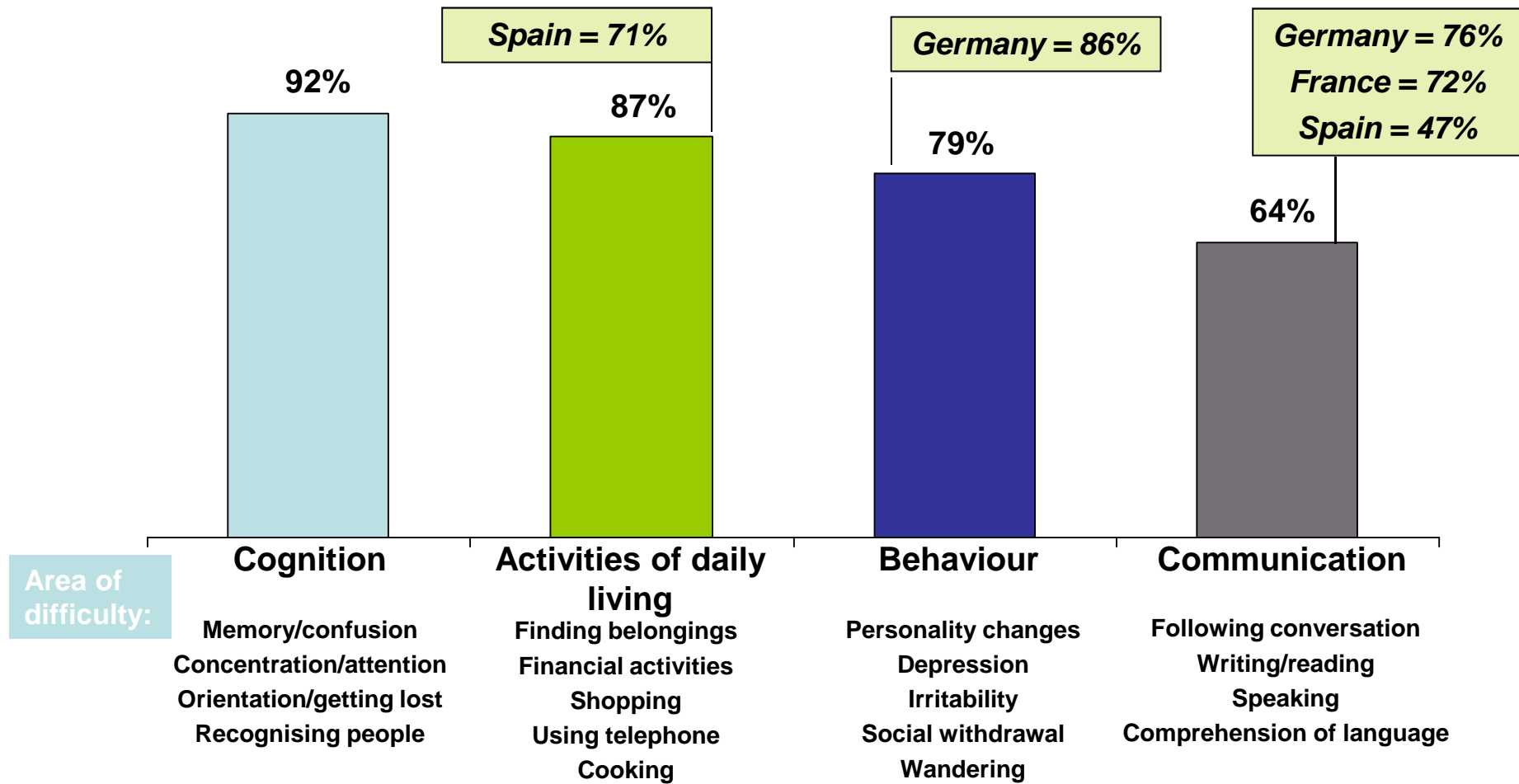
From problems to solutions

- Dementia as a public health priority and development of national and European action plans or strategies
- Increased research funding
- Dementia in medical training
- Exchange of best practices (care models, guardianship systems) through open method of coordination
- Support to Alzheimer associations

Carers' Survey

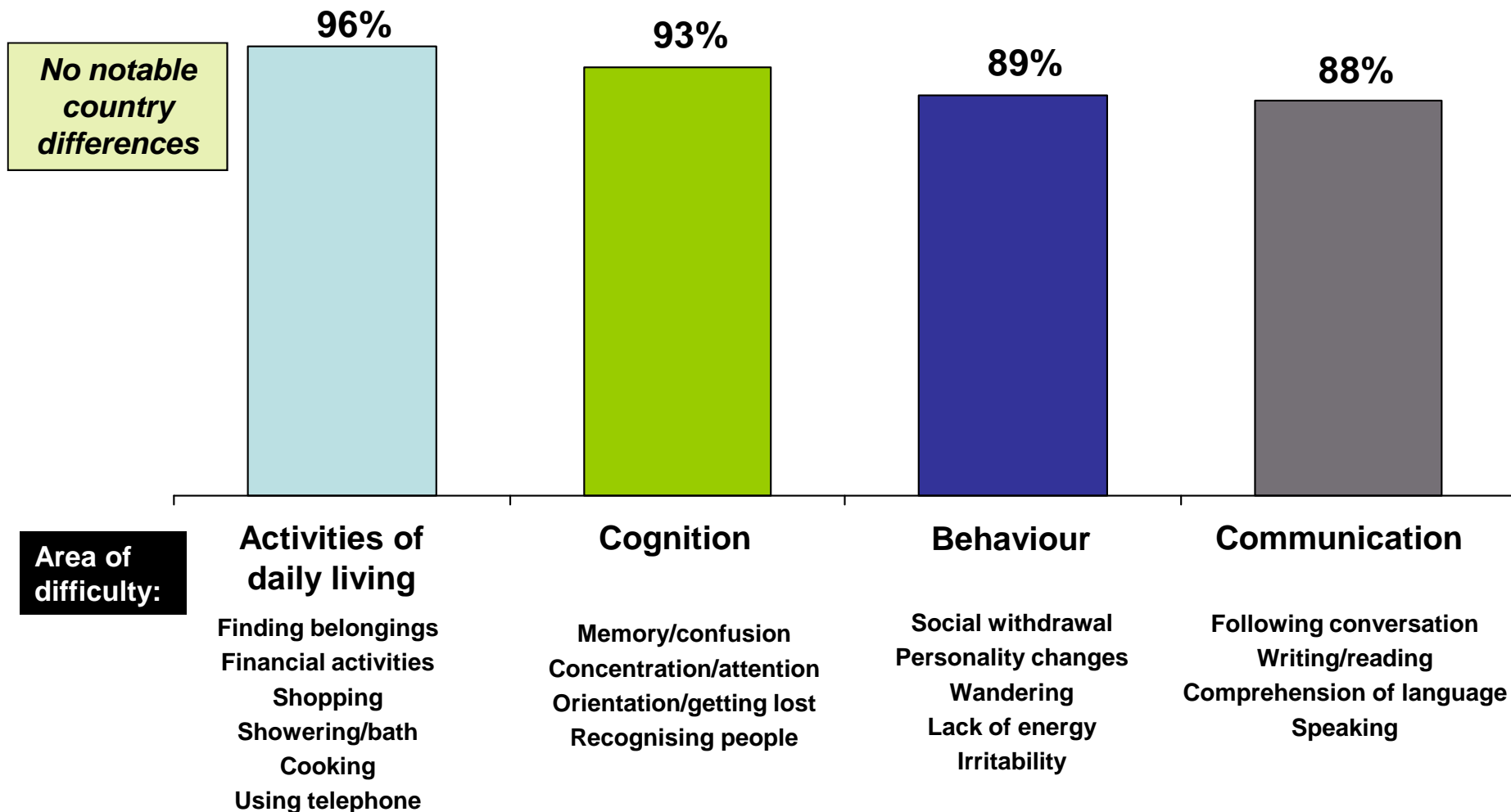
Country	Completed surveys
Germany	242
Poland	201
France	204
Scotland	334
Spain	200
TOTAL	1,181

Difficulties prompting the seeking of help: overview



Difficulties listed in order of decreasing importance

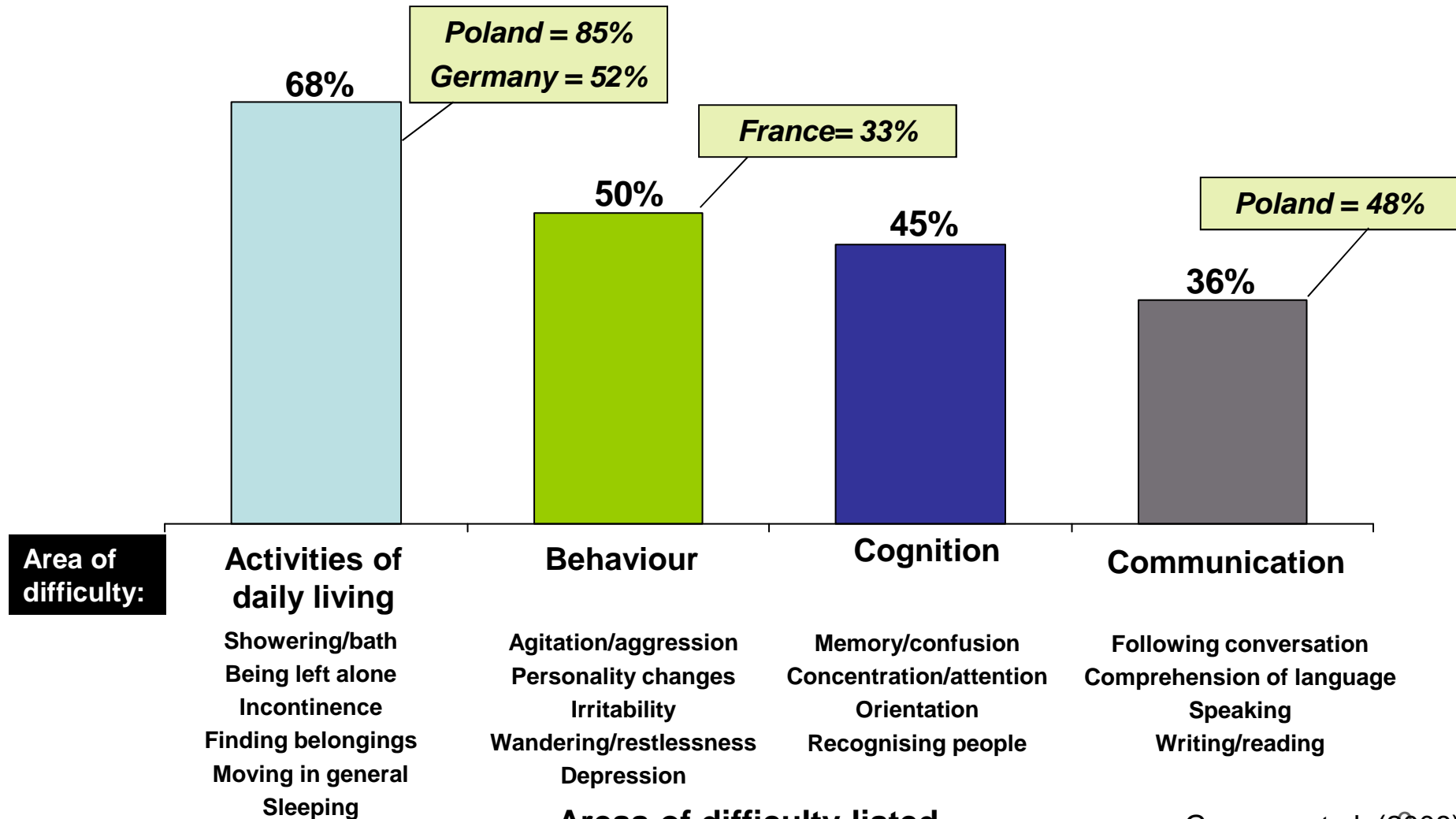
Current symptoms: overview



Areas of difficulty listed in order of decreasing importance

Georges et al. (2008),
Int J Geriatr Psychiatry

Most problematic symptoms: overview



Area of difficulty:

Activities of daily living

- Showering/bath
- Being left alone
- Incontinence
- Finding belongings
- Moving in general
- Sleeping

Behaviour

- Agitation/aggression
- Personality changes
- Irritability
- Wandering/restlessness
- Depression

Cognition

- Memory/confusion
- Concentration/attention
- Orientation
- Recognising people

Communication

- Following conversation
- Comprehension of language
- Speaking
- Writing/reading

**Areas of difficulty listed
in order of decreasing importance**

Georges et al. (2008),
Int J Geriatr Psychiatry

Most problematic symptoms: overview



Activities of daily living (68%)

- **Showering/bath** 25%
- **Being left alone** 20%
- **Incontinence** 19%
- **Finding belongings** 16%
- **Moving in general** 14%
- **Sleeping** 12%

Behaviour (50%)

- **Agitation/aggression** 16%
- **Personality changes** 16%
- **Irritability** 11%
- **Wandering/
restlessness** 10%
- **Depression** 8%

Cognition (45%)

- **Memory/confusion** 32%
- **Concentration/attention** 12%
- **Orientation** 12%
- **Recognising people** 7%

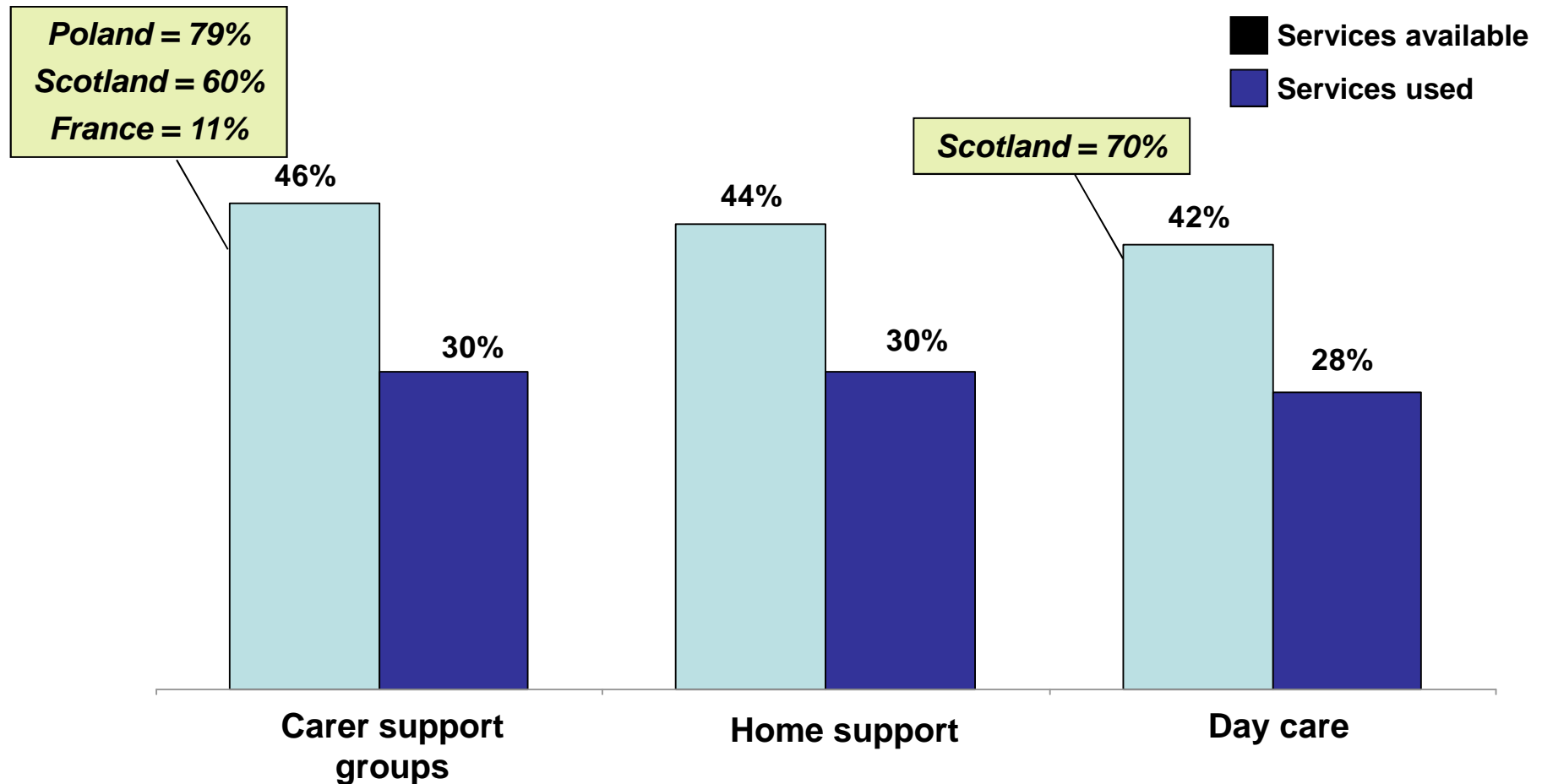
Communication (36%)

- **Following conversation** 17%
- **Comprehension of
language** 14%
- **Speaking** 12%
- **Writing/reading** 3%

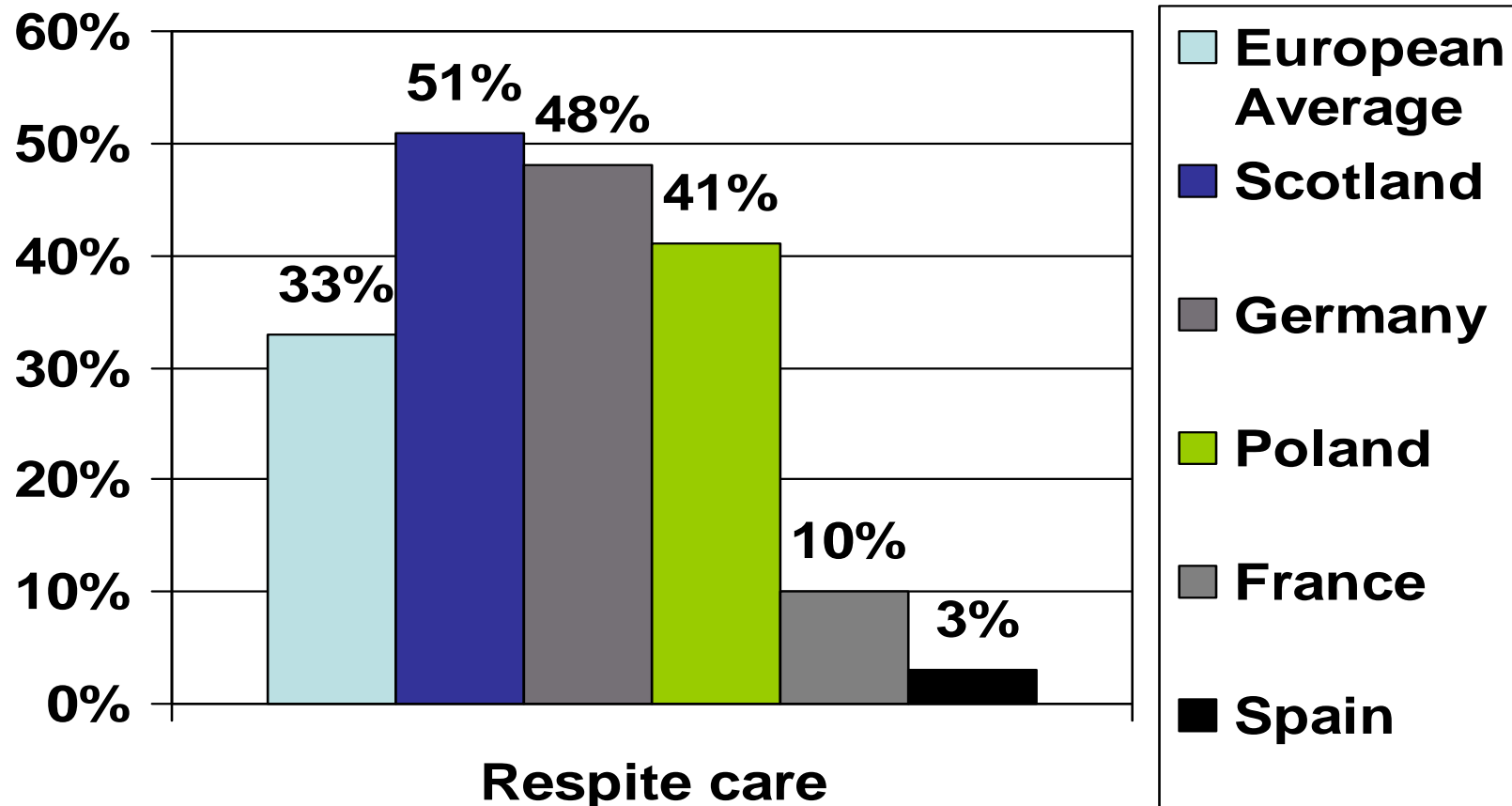
Base: all respondents (1,181)

Georges et al. (2008), Int J Geriatr Psychiatry

Availability and use of services (I)



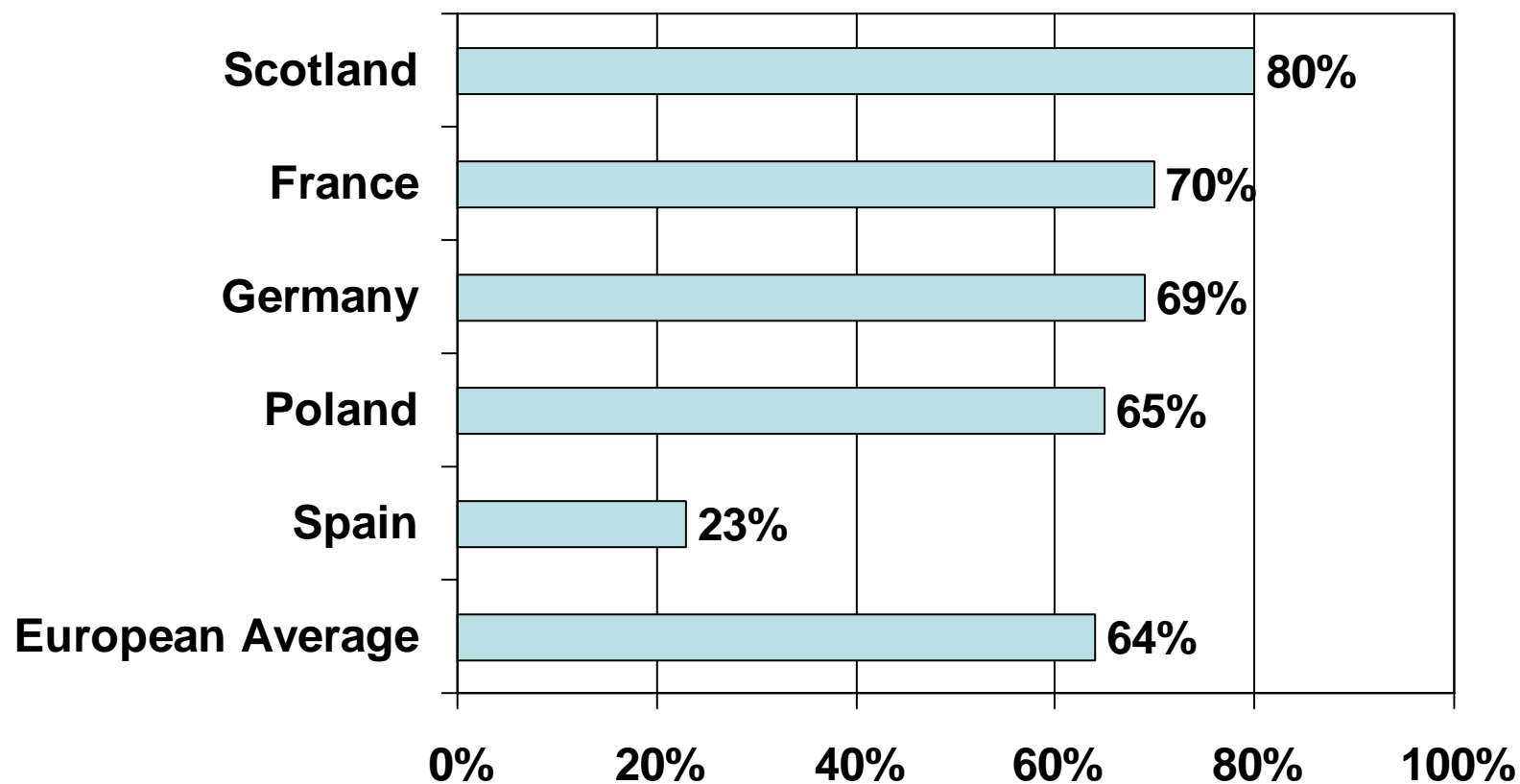
Availability and use of services (II)



Patients informed about disease



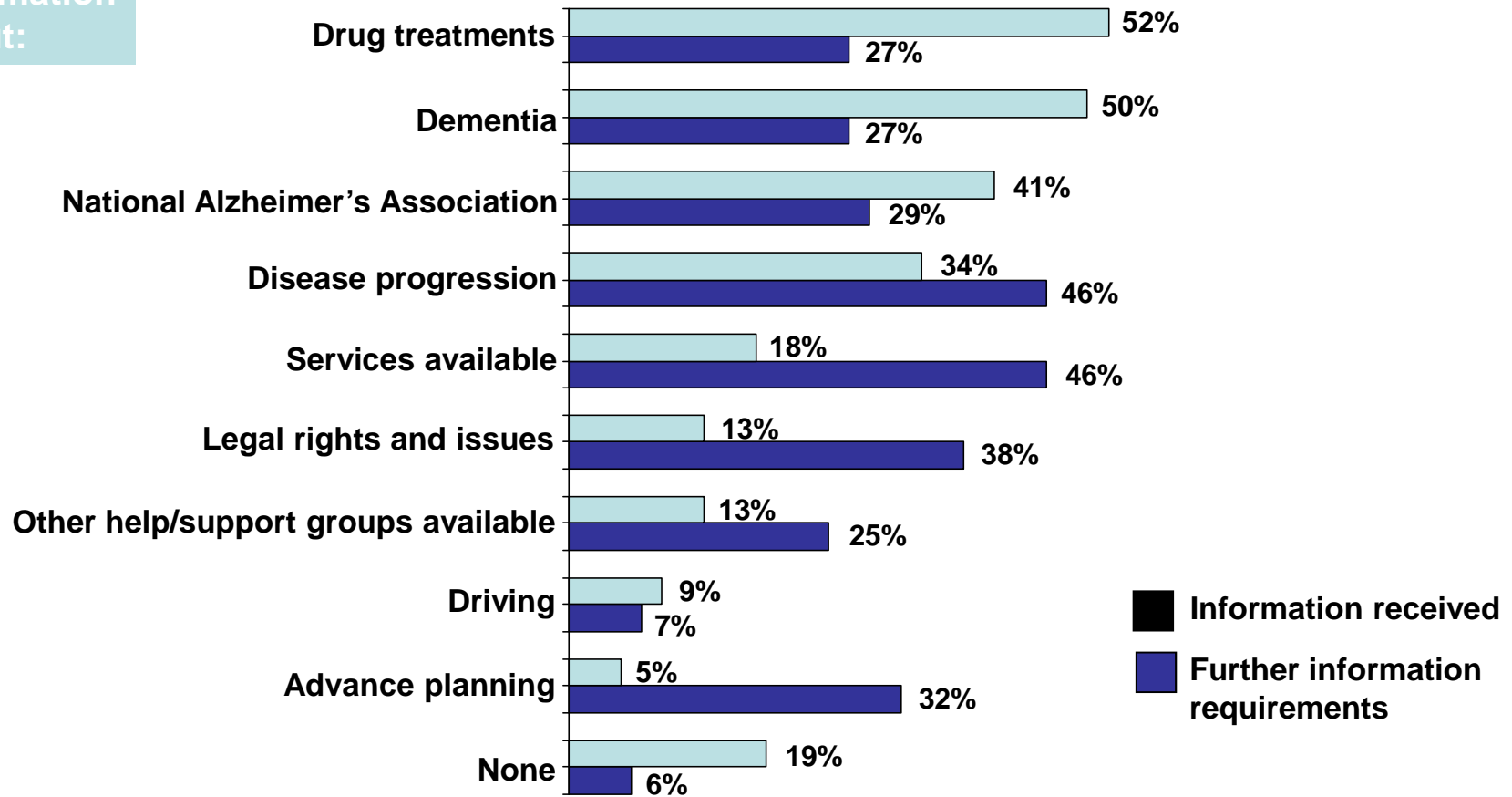
Percentage of carers reporting that patients were informed about disease



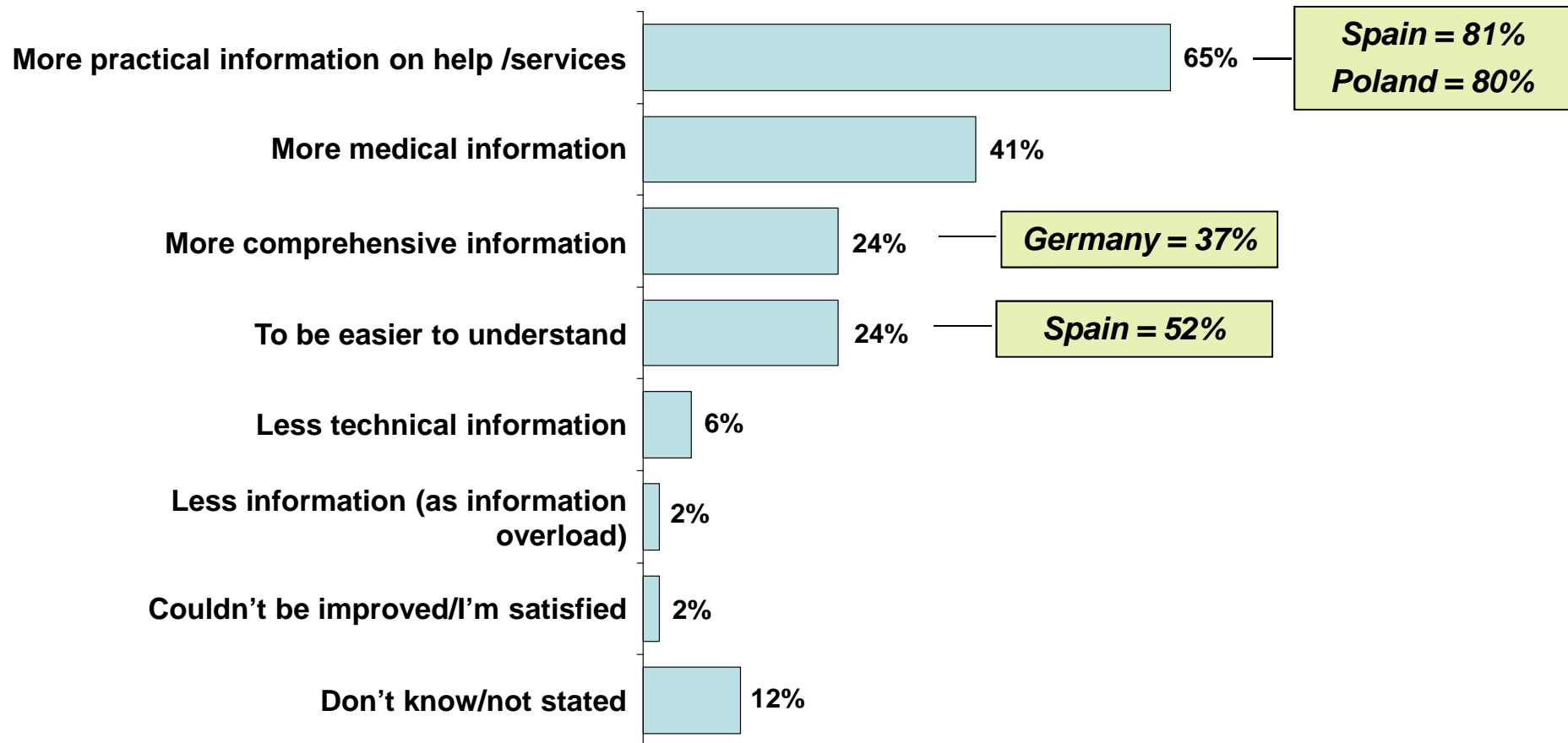
Information received upon diagnosis & additional information requirements



Information about:



Ways in which information received could be improved



European Collaboration on Dementia

1. Prevalence of dementia
2. Diagnosis and treatment
3. Non pharmacological interventions
4. Risk factors and prevention
5. Socio economic cost of dementia
6. Social support of people with dementia and their carers

Diagnostic and treatment guidelines

- **39 guidelines identified and included in database allowing comparison on individual items**
 - 22 European guidelines
 - 14 non-English language
 - 8 English language
 - 17 non-European English language guidelines

Psychosocial guidelines

- **Inventory of guidelines**
 - In 5 European countries, dementia guidelines were found that gave attention to psychosocial interventions (Germany, Italy, Netherlands, Spain and United Kingdom)
 - In 3 European countries, reports giving attention to psychosocial care in dementia are available (France, Ireland and Switzerland)

Social support systems



- **Inequalities in access persist**
 - Differences between countries
 - Regional variations within countries
- **Fragmentation of social support**
 - Various government departments (health, social affairs, social security, employment)
 - Responsibility on federal, regional and local level
 - Public, private and NGO run services
- **Lack of specialisation**
 - General services for people with disabilities or the elderly
 - Lack of training of care personnel in dementia specific care 19

For more information

www.alzheimer-europe.org

www.dementia-in-europe.eu



The screenshot shows the Alzheimer Europe website. The header features the Alzheimer Europe logo on the left, the title 'Dementia in Europe' with the tagline 'Making dementia a public health priority' in the center, and a language dropdown menu set to 'English' on the right. Below the header is a navigation menu with options like 'HOME', 'Our Campaign Priorities', 'Support our Campaign', 'Prevalence of Dementia', 'Availability of anti-dementia Drugs', 'Home Care in Europe', and 'Alzheimer Europe Press Releases'. The main content area is titled 'Making Dementia a Public Health priority' and contains three paragraphs of text. The right sidebar includes a 'Search' box, a 'Download' section with links for campaign priorities in English, French, and Czech, a 'Links' section with a link to Alzheimer Europe, and a 'Services' section with a link to support the campaign.

HOME

Making Dementia a Public Health priority

This new website of Alzheimer Europe is dedicated to the public health impact of Alzheimer's disease and other forms of dementia in Europe. On this website, you will find the Paris Declaration on the political priorities of the European Alzheimer movement. This document was adopted unanimously at the Annual Meeting of Alzheimer Europe in Paris in June 2006 and is a veritable call for action on European policy makers to give dementia the public health priority it so justly deserves.

We are particularly proud of the fact that Philippe Bas, Minister for Social Affairs and the Elderly in France gave his personal support and that of the French government to our initiative. At the launch of our Declaration in the European Parliament on 7 November, we were furthermore able to gather the support of a number of key Members of the European Parliament.

A full list of policy makers, associations and individuals who support our call for action can be found on our website and we invite anyone with an interest in Alzheimer's disease or dementia to pledge your support to our campaign online.

As a resource to the visitors to this website, we also provide information on the prevalence of dementia, the reimbursement of anti-dementia drugs and the provision of home care in 31 European countries. Finally, we will pay close attention to policy developments in Europe and report on them on this website.

We sincerely hope that this website will become an essential tool for policy makers, journalists and researchers interested in dementia and that together we will make dementia a public health priority.

English

Home

Search

Search

Download

- Campaign priorities in English
- Campaign priorities in French
- Campaign priorities in Czech

Links

Alzheimer Europe

Services

Support our campaign