

# Dementia and long-term care in Europe

EAHSA-E.D.E. Congress, Prague  
14 September 2018



Jean Georges, Executive Director

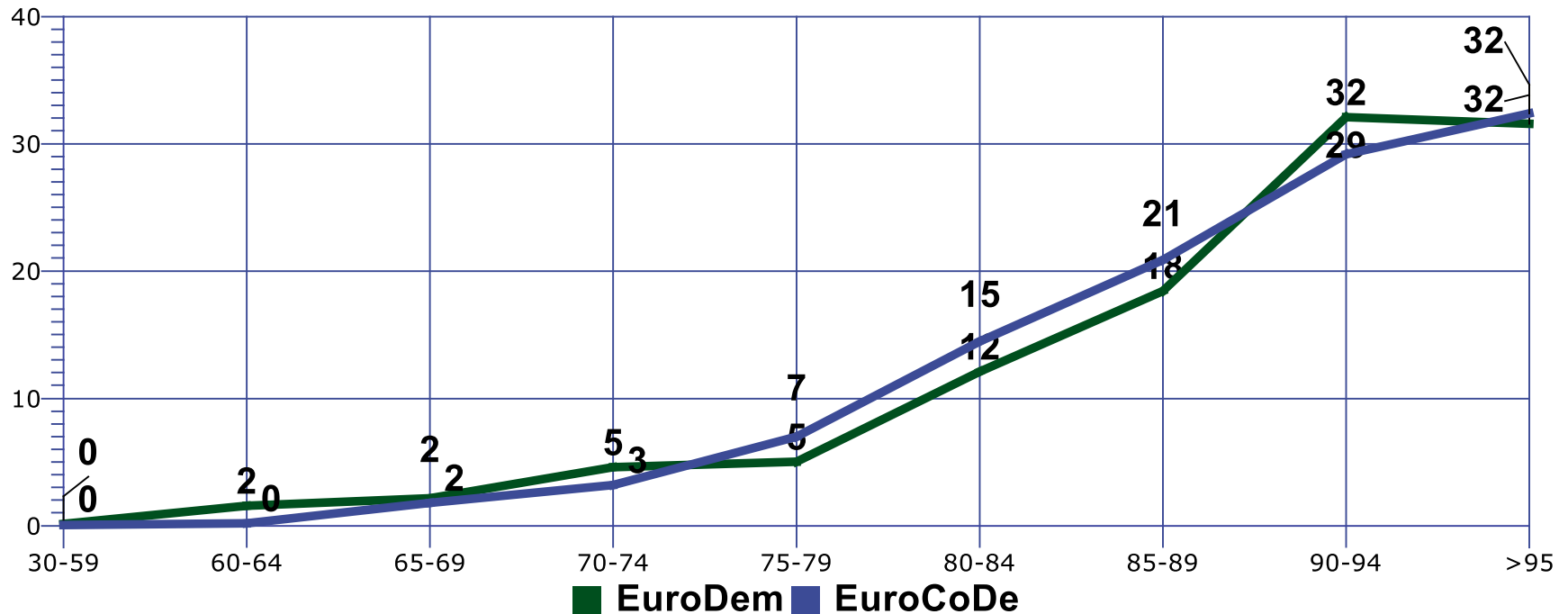
@JeanGeorgesAE

# Overview

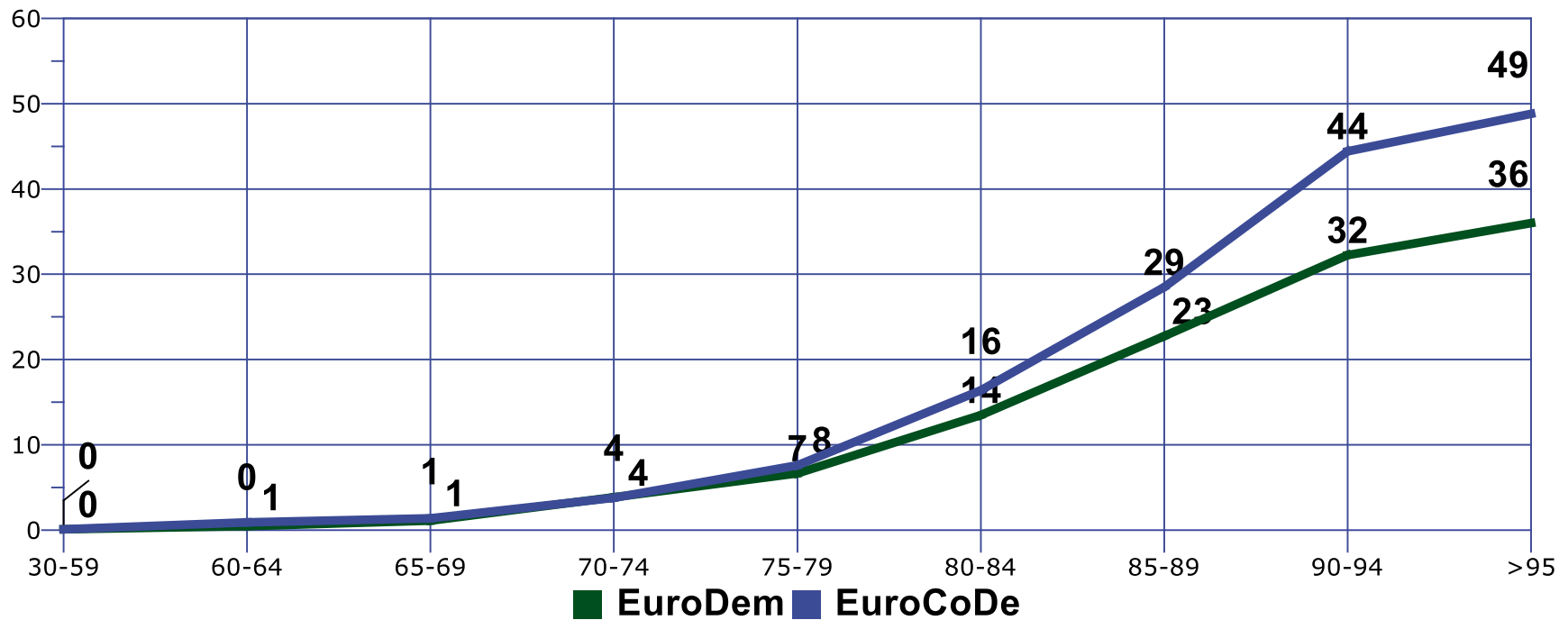
- Dementia and Alzheimer's disease, some statistics
- Alzheimer Europe
- Inequalities in access to care across Europe – Findings of the European Dementia Monitor
- Standards for residential care facilities in Europe – Findings of Alzheimer Europe's 2017 Dementia in Europe Yearbook
- Concluding comments

# **Dementia and Alzheimer's disease**

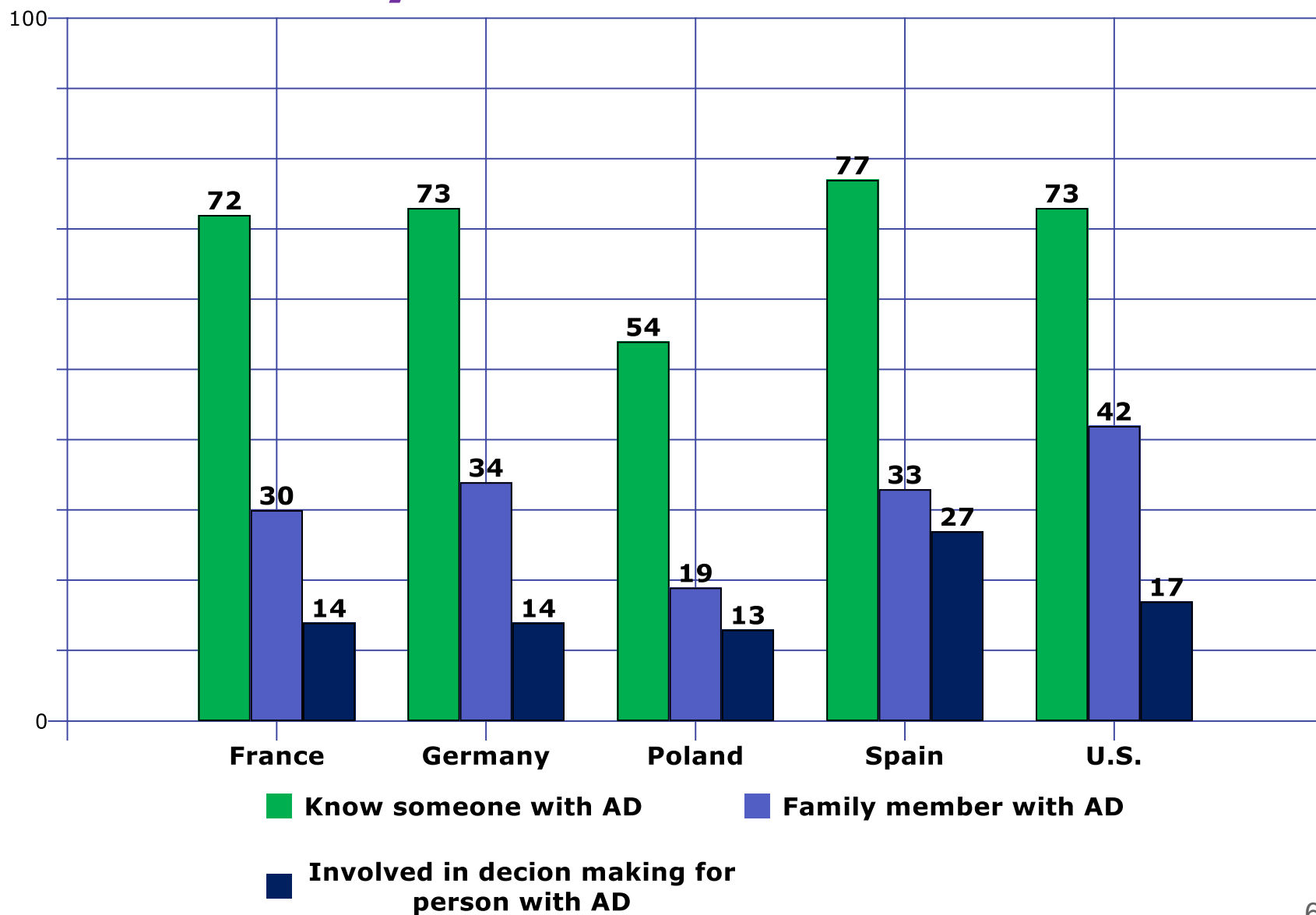
# Prevalence of dementia (men)



# Prevalence of dementia (women)



# Familiarity with Alzheimer's disease



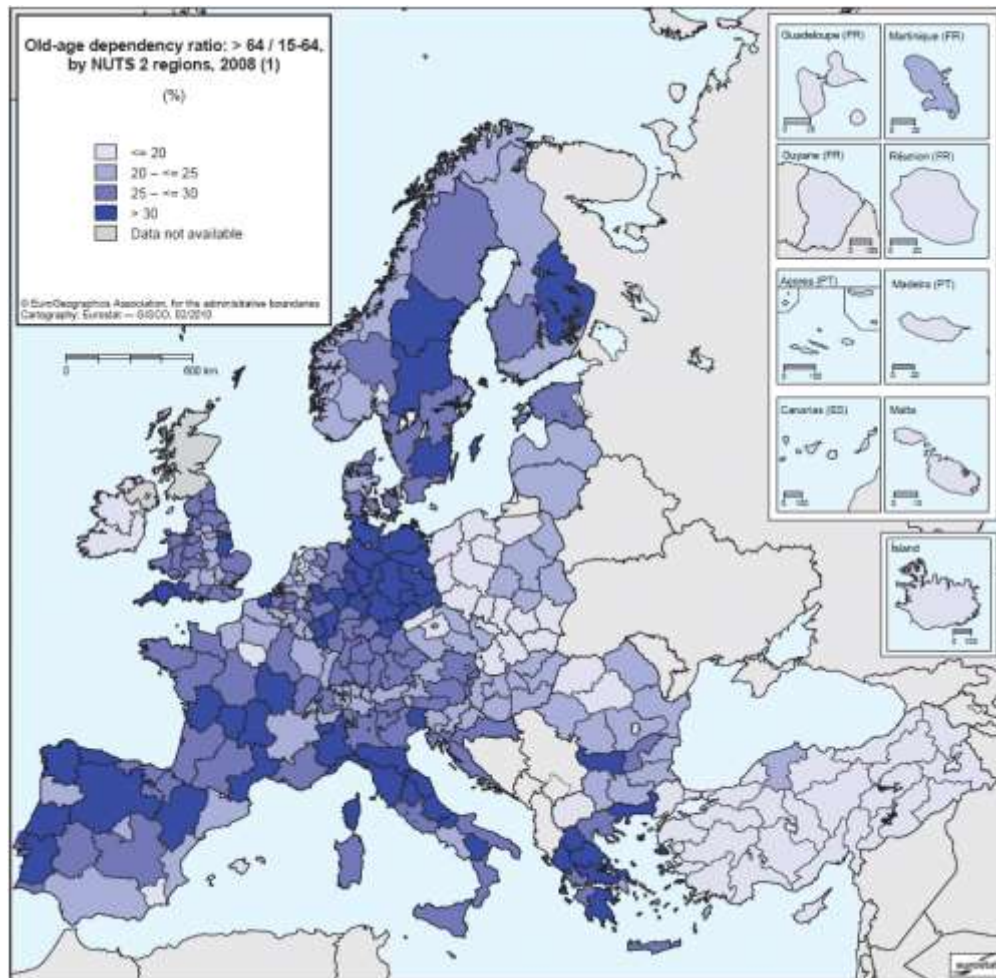
# Public health impact

- 8.6 million people with dementia in European Union (2015)
- Numbers expected to at least double by 2040



Ferri et. al. (2005) Global prevalence of dementia: a Delphi consensus study, The Lancet, Vol. 366, December 17/24/31, 2005

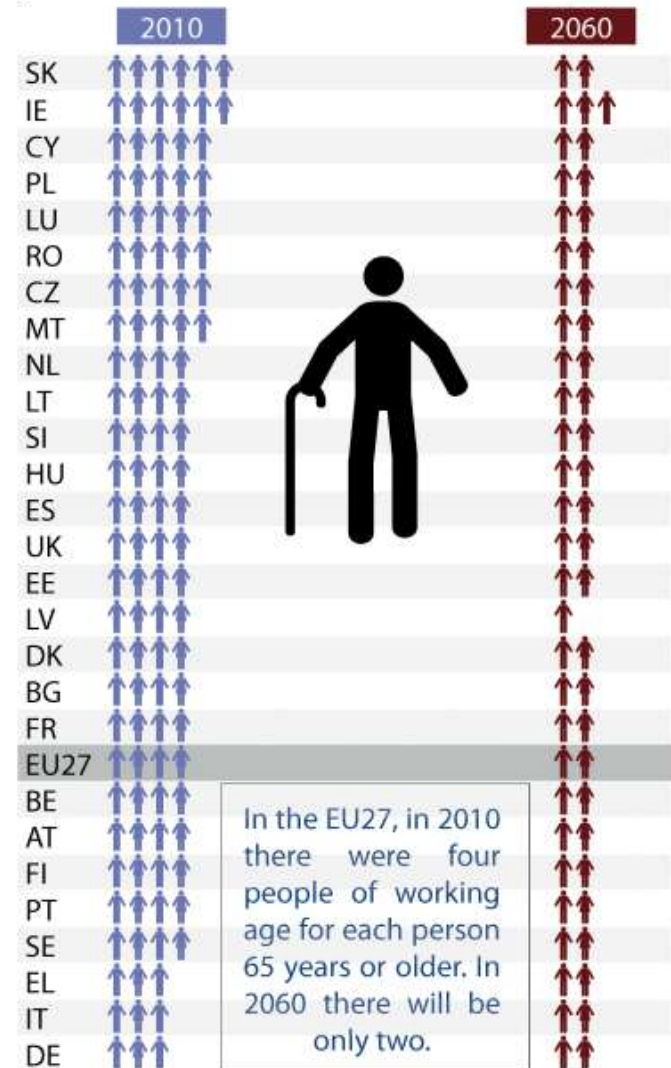
# Old-age dependency ratios



(1) France, the United Kingdom, Liechtenstein, Norway and Turkey, 2007.

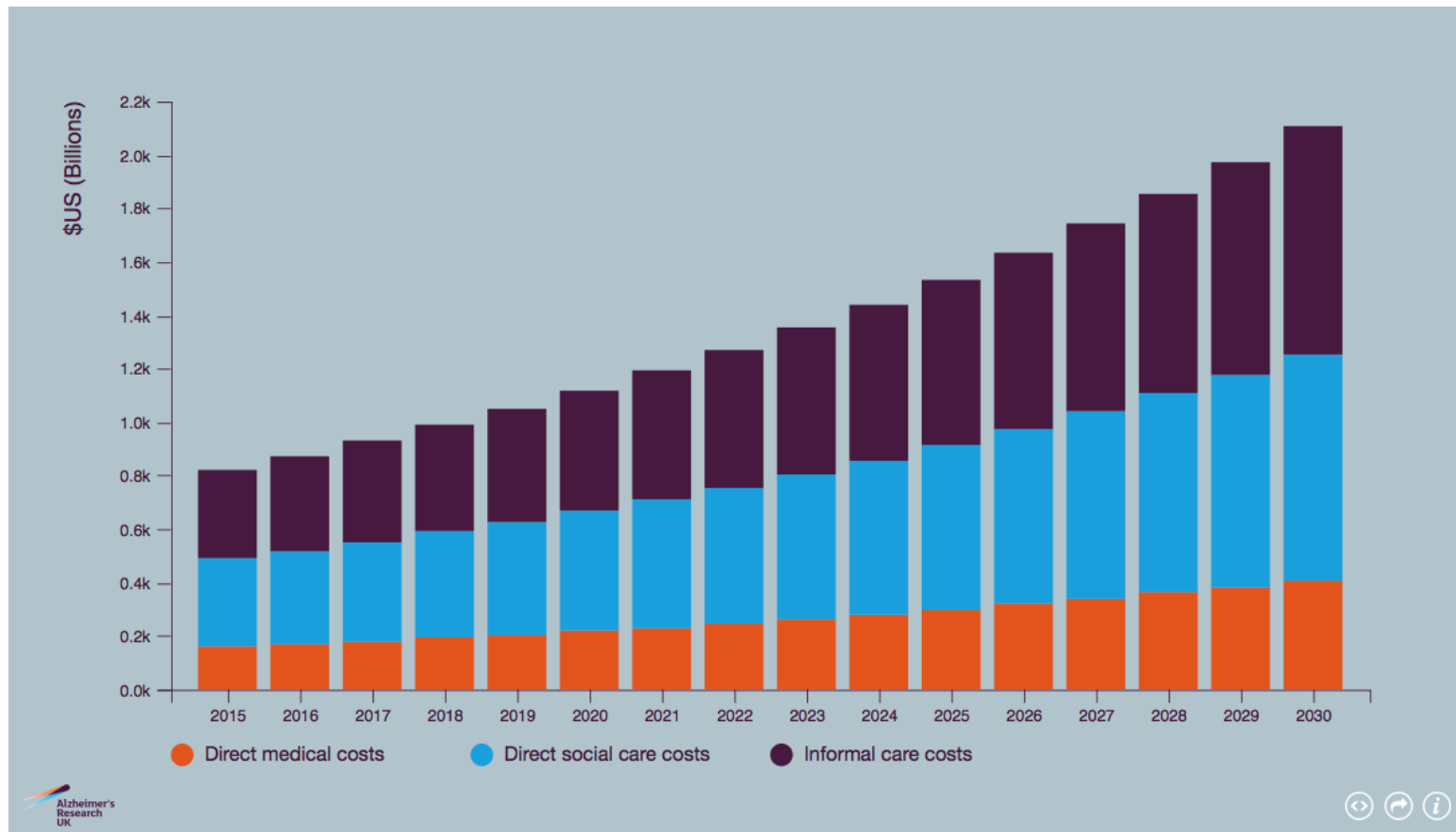
## Old-age dependency ratio ( $65+/(15-64)$ )

Number of people of working age for each person 65 years or older

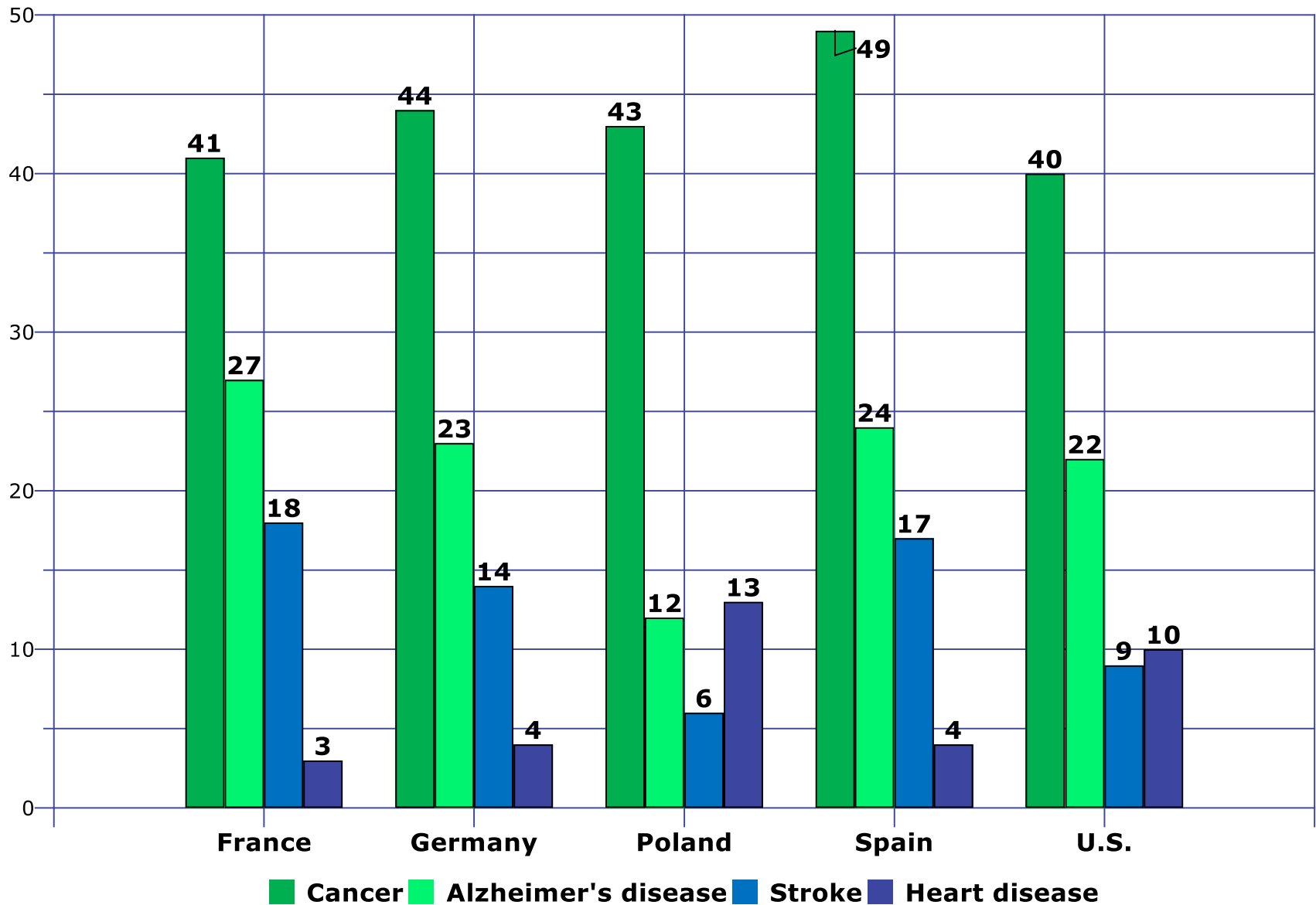




# Cost of dementia



# Most feared diseases



# Alzheimer Europe

## Alzheimer Europe

40 associations in 35 countries



# Strategic objectives

- Providing a voice to people with dementia and their carers
- Making dementia a European priority
- Promoting a rights based approach to dementia
- Strengthening the European dementia movement
- Supporting dementia research

# **Inequalities in access to care across Europe – Findings of the European Dementia Monitor**

# European Dementia Monitor

- Benchmarking of national dementia policies (comparison and ranking)
- Lobbying tool for AE to present comparative data to European Parliament and European Commission (inequalities in access to care and treatment)
- Lobbying tool for national Alzheimer associations (compare national situation to other countries)
- Collaboration of AE and national Alzheimer associations
- Simple information based on available statistics/information
- Verifiable data from trustworthy sources

# European Dementia Monitor

## Priority areas

- Availability of care services
- Affordability of care services (financing)
- Treatment-reimbursement of AD medicines
- Access to clinical trials
- Involvement of country in EU dementia research
- Recognition of dementia as a priority
- Dementia friendly Communities/Inclusiveness
- Recognition of legal rights
- Recognition of human rights
- Employment carer/employment support



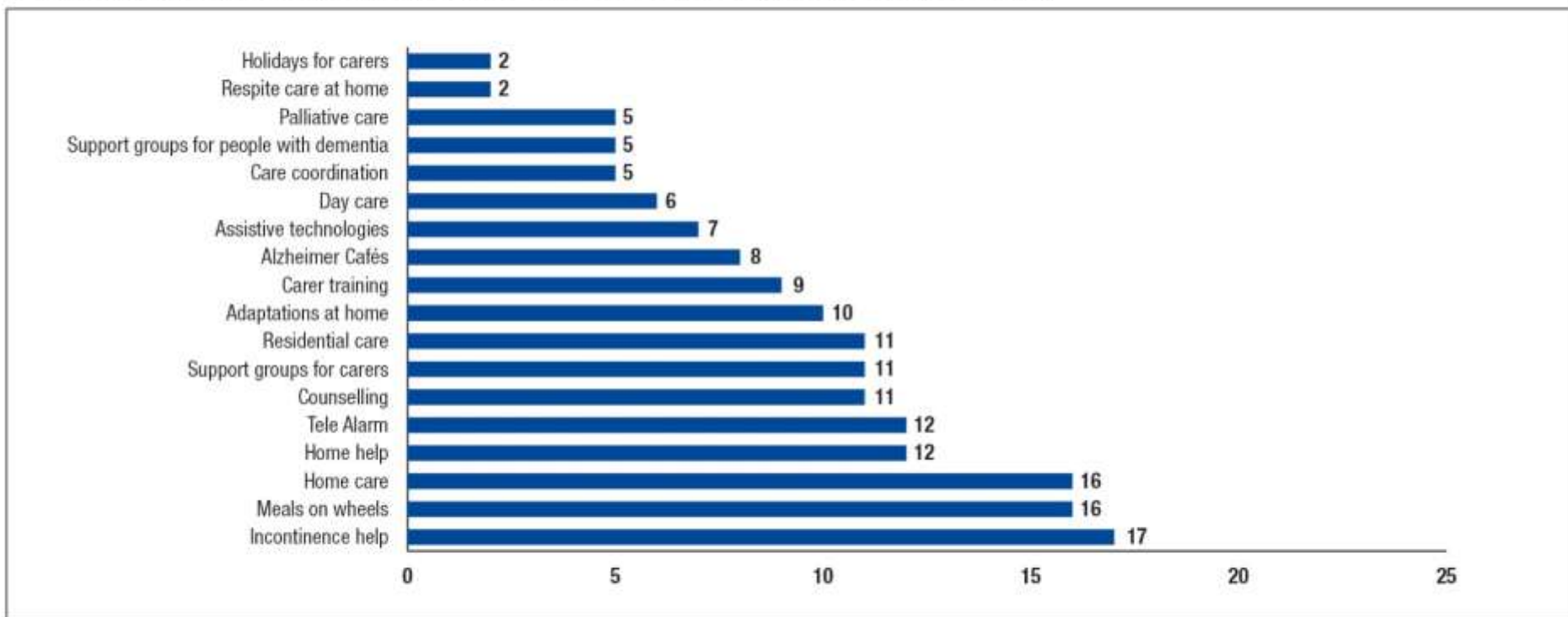
# Care availability/ Affordability

1. Care coordination/Case management	10. Support groups for people with dementia
2. Home help	11. Support groups for carers
3. Meals on wheels	12. Respite care at home (sitting service etc)
4. Incontinence help	13. Holidays for carers
5. Assistive technologies / ICT solutions	14. Carer training
6. Tele Alarm	15. Alzheimer Cafés
7. Adaptations to the home	16. Day care
8. Home care (Personal hygiene, medication)	17. Residential/Nursing home care
9. Counselling	18. Palliative care

Sufficient, insufficient, absent / Fully funded, partly funded or means tested, no public funding

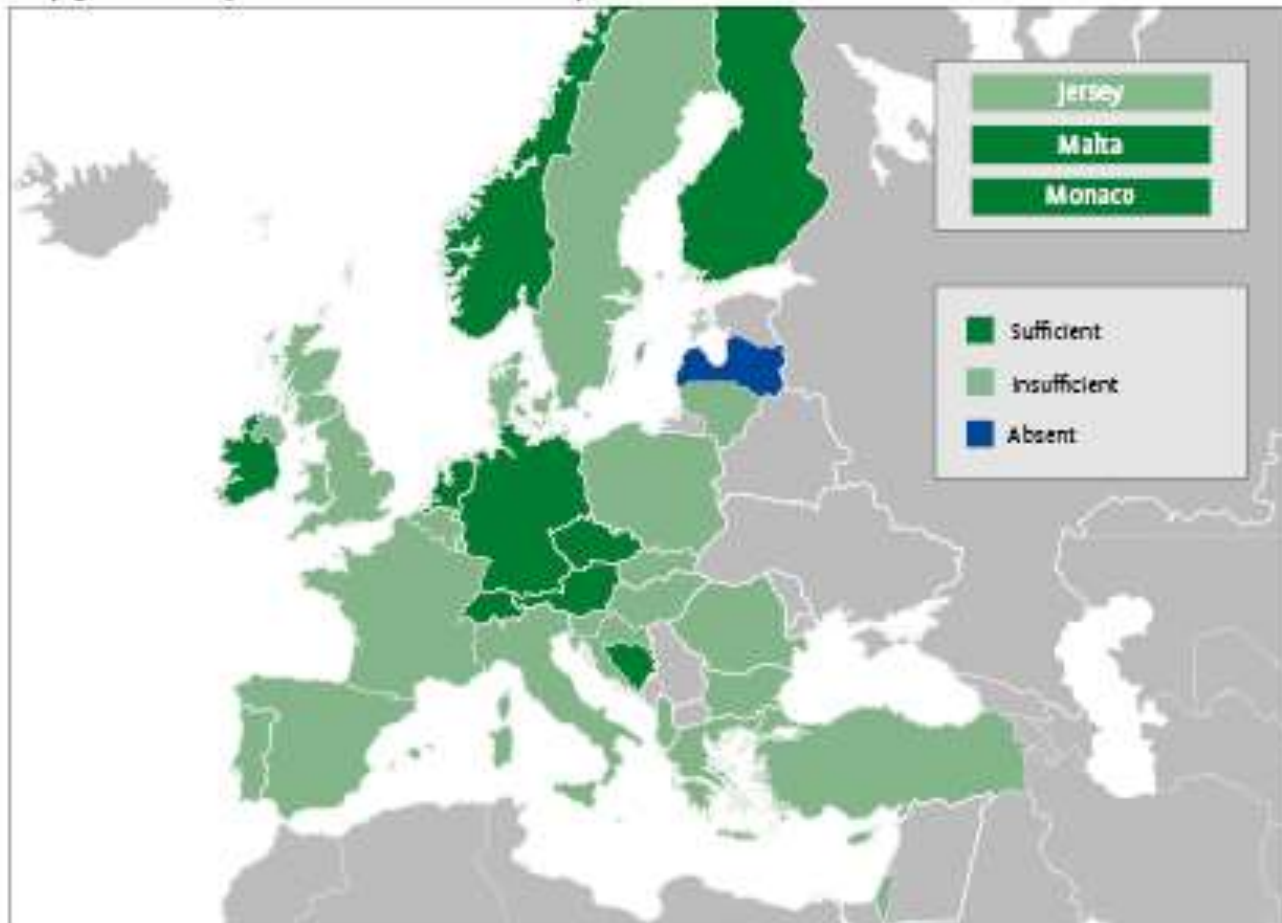
# Care services available in European countries

Figure 1: Number of countries rating service as sufficiently available (out of 36)

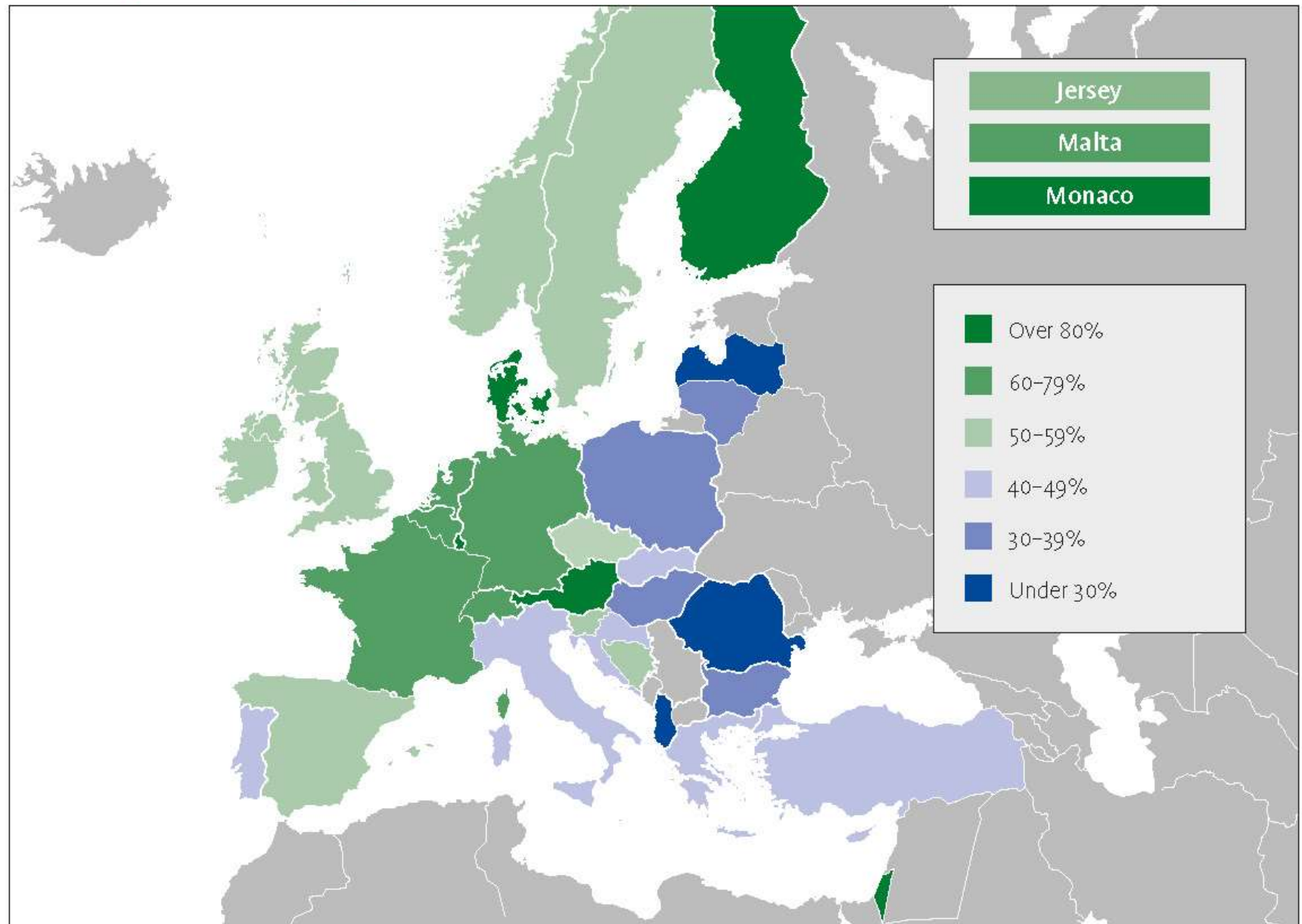


# Availability of residential care

Map 3: Availability of residential care in Europe

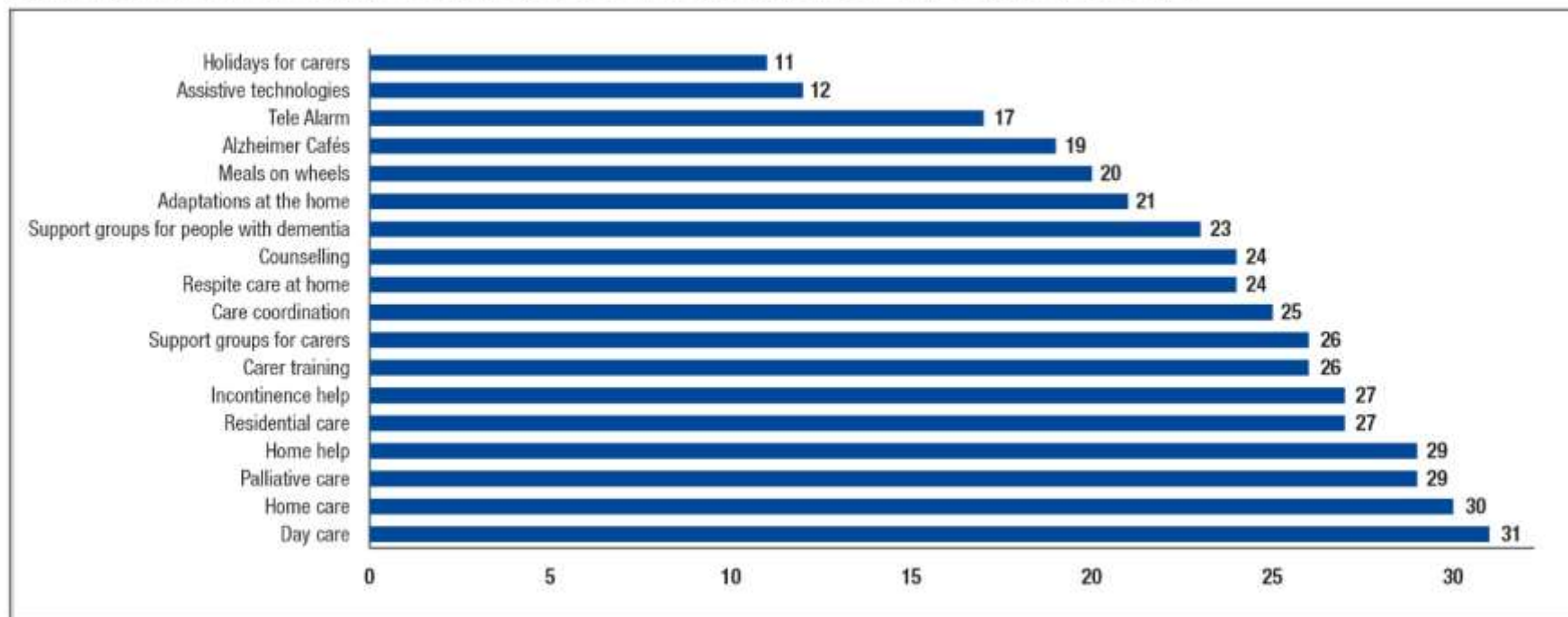


## Ranking on availability of care services

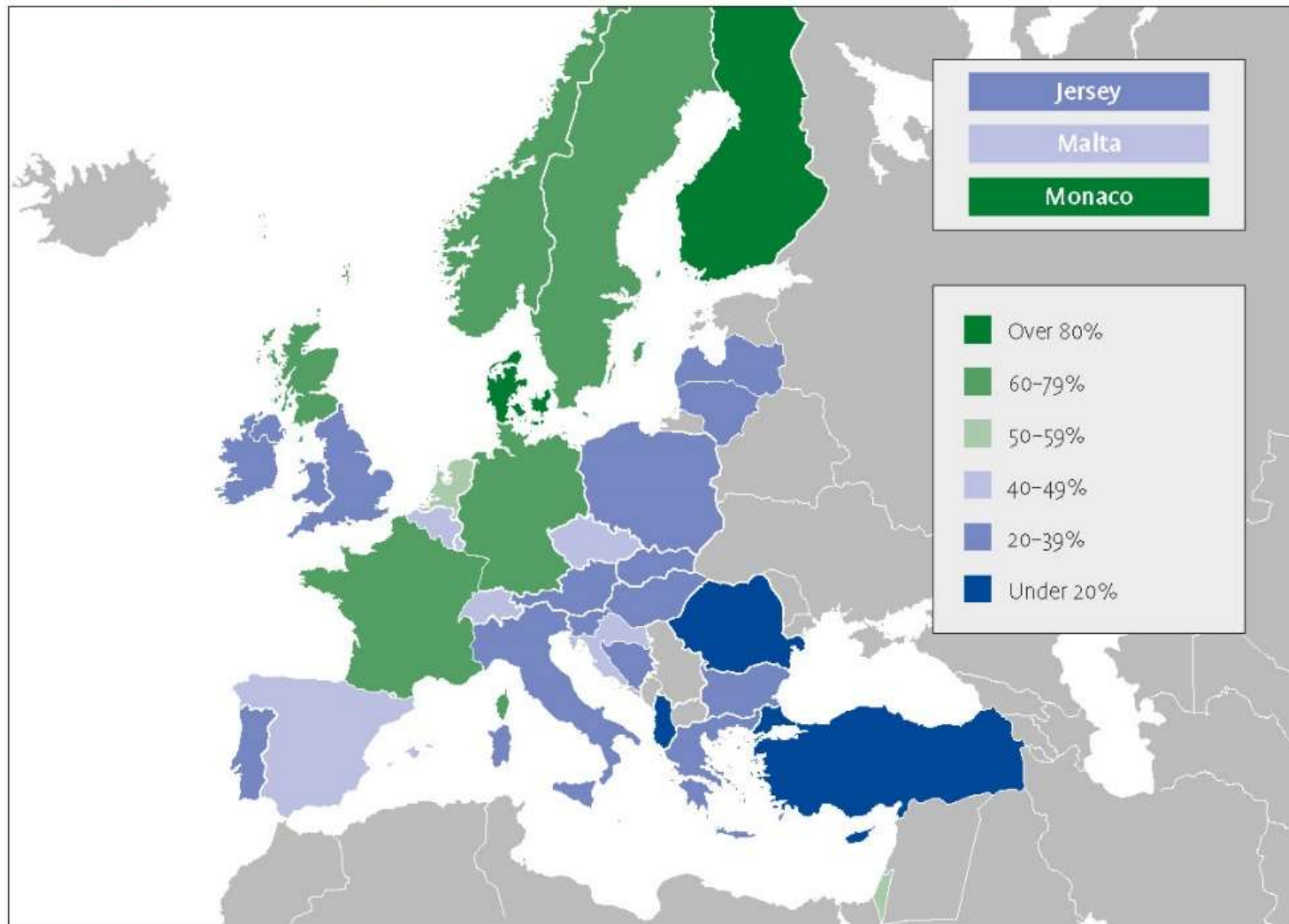


# Public support for care services in European countries

Figure 3: Number of countries in which there is public support for care service (out of 36)



## Ranking on affordability of care services



# **Standards for residential care facilities in Europe – Findings of Alzheimer Europe's 2017 Dementia in Europe Yearbook**



# 2017 Dementia in Europe Yearbook

- Overview of legislative frameworks/standards for residential care facilities in Europe
  - Physical environment
  - Workforce
  - Provision of care
  - Rights
  - End-of-life care
  - Abuse and restraint





# Prevalence of dementia in LTC facilities

- 13.4% in Hungary (2008)
- 56% (health centres) to 68% (nursing homes) in Finland (2012)
- 22% with severe dementia and 70% with significant cognitive impairment in Italy (2012)
- 35.6% in residential homes to 57% in nursing homes in the Netherlands (2012)

# Dementia in legislative frameworks and standards

- Not always sufficiently addressed in general regulations on residential care
- Focus on care for people with dementia with challenging behaviour (HR, FR, IT, NL, NO, SK, SI)
- Care standards with references to pwd (IE, MT, UK-NI and Wales)
- General dementia care standards/guidelines may apply to pwd in institutions

# Monitoring of LTC facilities

- National or regional inspection systems
- Inspection after complaint(s) in all countries
- Frequency of inspections: every 6 months (Cyprus or Romania) to at least once in three years (Slovenia)
- Inspection report or ratings only rarely made public
- Involvement of residents/families in monitoring/decision making remains exception (BE, FR, DE, HU, LT)

# Physical environment

- Included principles: Safety, dignity, privacy, accessibility
- Standards for lighting, heating and temperature
- Requirements for private rooms:
  - from 4m<sup>2</sup> in Cyprus to 25m<sup>2</sup> in Finland
  - from single use in Finland (unless wish to share with other resident) to maximum of 6 in Spain (Madrid)
- Requirements for common rooms
  - From 1.5m<sup>2</sup> in Slovenia to 5m<sup>2</sup> in Luxembourg

# Workforce

- **Qualification requirements for manager of LTC facility**
- **Needed professionals**
  - Onsite or oncall MD: BE (FL), HR, FR, GR, HU, LV
  - Onsite or oncall nurse: BE (FL), HR, FR, DE, GR, LV, LU, NL, NO, PL, SK, CH, TU
- **Staff ratios**
  - 1 staff for ten more dependent residents in Turkey to 1 staff for two residents in Germany, Lithuania or Romania

# Needs assessment and care plans

- **Common elements**
  - Nursing and medical care needs
  - Personal characteristics and life history
  - Interest in leisure and social activities
- **Less common elements**
  - Involvement of person in needs assessment
  - Ethnic and cultural background
  - End-of-life preferences

# Underdeveloped areas

- Use of restraint in residential care settings
- Protection from abuse (financial, physical and sexual abuse as well as negligence)
- End-of-life care (Involvement of family and friends and staff training)
- Use of antipsychotics
- « Dementia-friendliness » of services

## Concluding comments



# Concluding remarks

- **Significant inequalities in access to and quality of (residential) care for pwd across European countries**
  - Need for dementia strategies and increased dementia awareness in all European countries
  - Exchange of good practices between countries should be encouraged
- **Growing recognition of dementia as an EU priority**
  - Need for increased funding and improved coordination at European and global level
  - Long-term care needs to be a research priority at EU level alongside research into causes and cure of Alzheimer's disease/dementia