



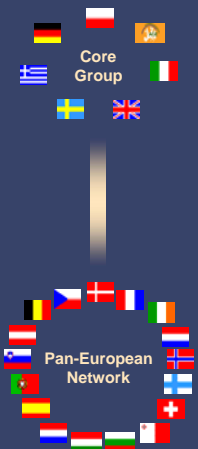
*European Master in Gerontology: 4th Summer Course - Malta, 10th June 2005*

# Family Care of Older People in Europe

## Results and Implications of the European Research Program **EUROFAMCARE**

Hanneli Döhner<sup>1</sup>, Eva Mnich<sup>1</sup>, Christopher Kofahl<sup>1</sup> & Giovanni Lamura<sup>2</sup>  
(1) University of Hamburg, Germany (Co-ordination Centre)  
(2) Italian National Research Centre on Ageing - INRCA Ancona  
on behalf of the EUROFAMCARE group

The **EUROFAMCARE** group: **Germany**: Döhner H. (project co-ordinator), Kofahl C., Luedecke D., Mnich E. (Hamburg) and Rothgang H., Becker R. (Bremen); **Greece**: Mestheneos E. (PI), Triantafillou J. (PI), Prouskas C., Mestheneos K.; **Italy**: Lamura G. (PI), Balducci C., Melchiorre M.G., Quattrini S., Spazzafumo L.; **Poland**: Bien B. (PI), Wojszel B., Synak B., Czekanowski P., Bledowski P., Pedich W.; **Sweden**: Öberg B. (PI), Krevers B., Johansson S.L.; **United Kingdom**: McKee K. (PI), Barber L., Brown J., Nolan M.





# The 5<sup>th</sup> Framework Programme: Quality of Life and Management of Living Resources

## Services for Supporting Family Carers of Elderly People in Europe:

### Characteristics, Coverage and Usage

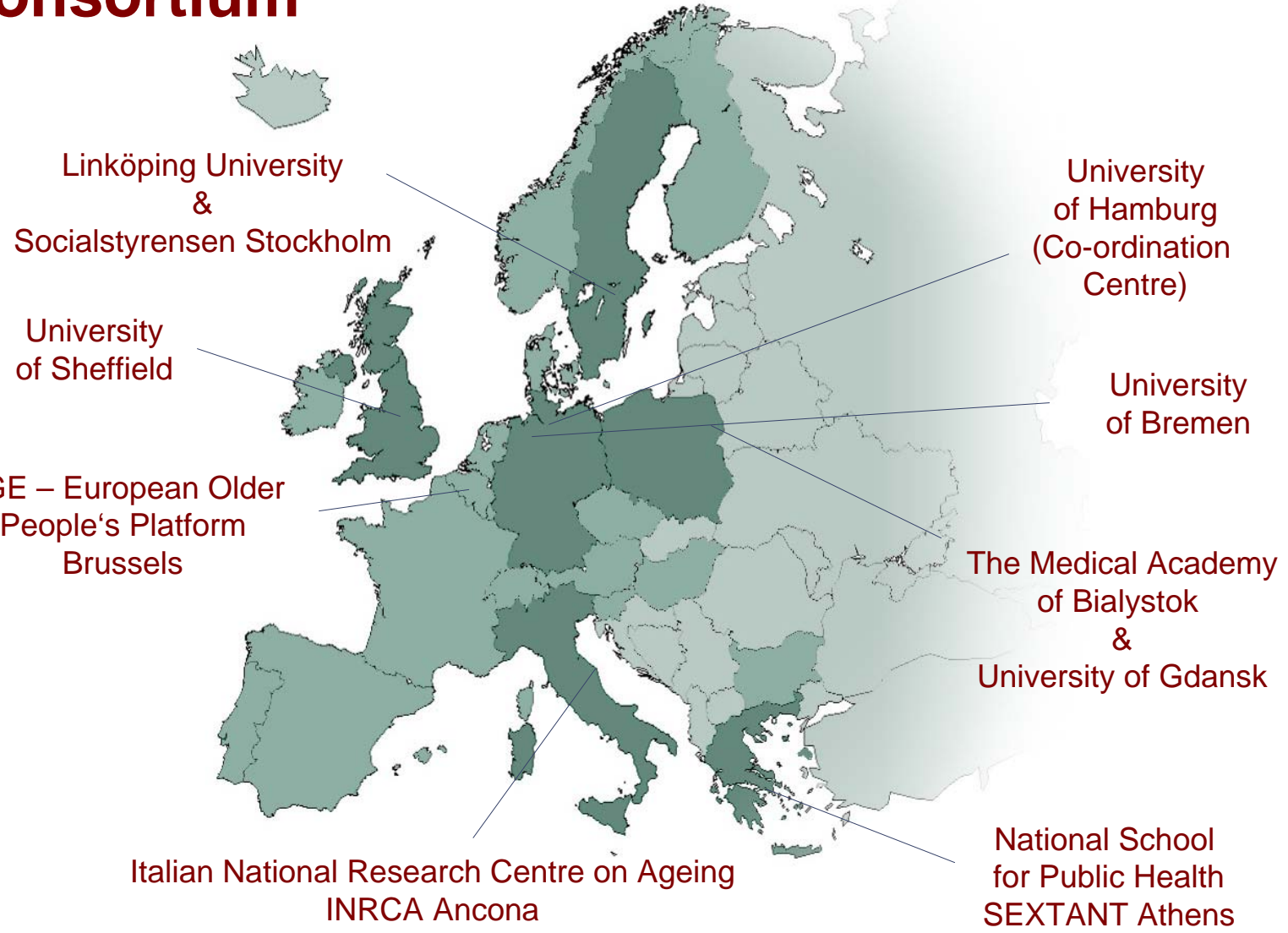
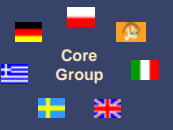
# EUR FAMCARE

**Key Action 6: The Ageing Population and Disabilities**  
**6.5: Health and Social Care Services to older People**

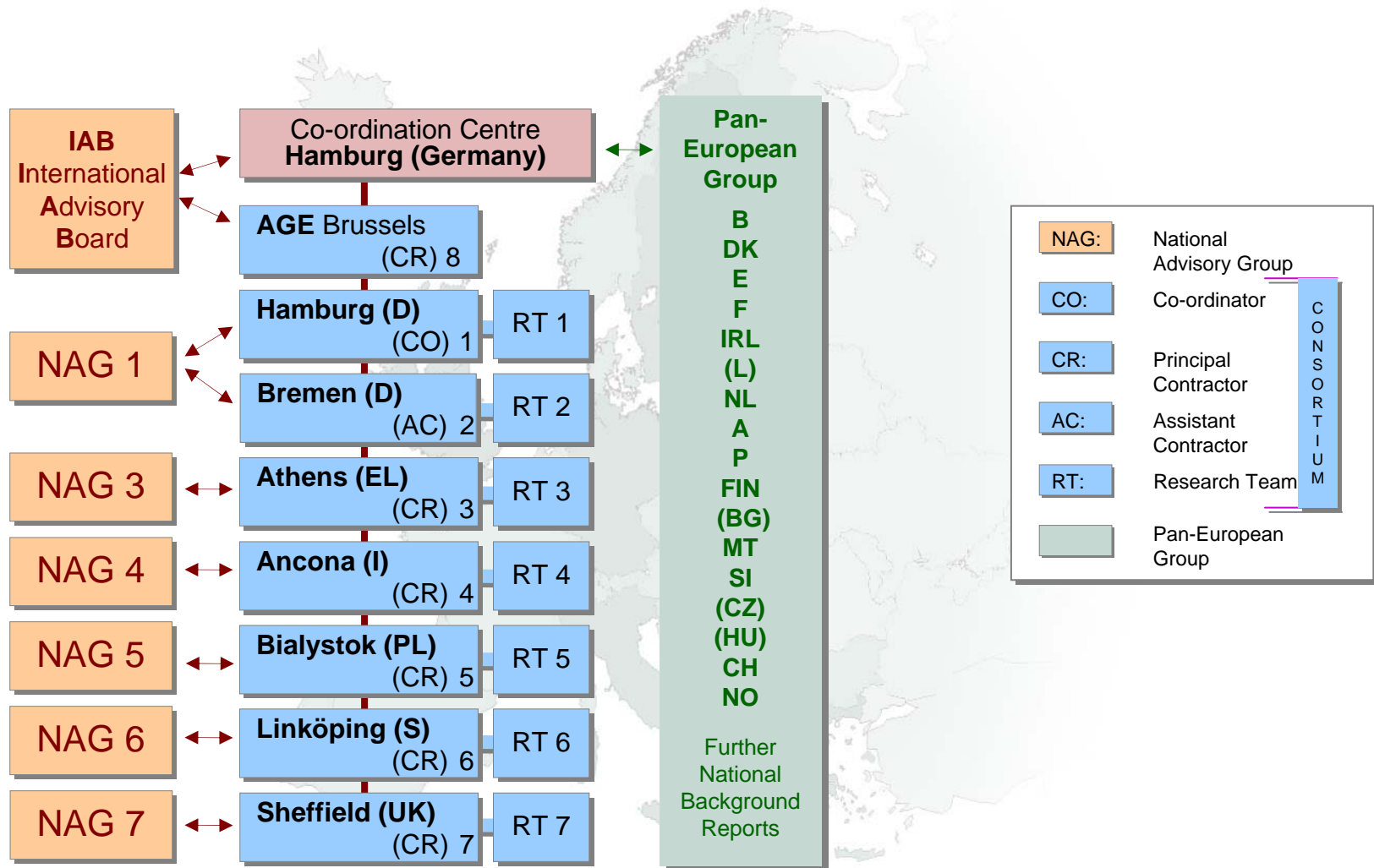




# Consortium



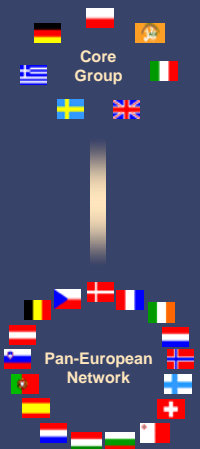
# The collaboration-model of EUROFAMCARE

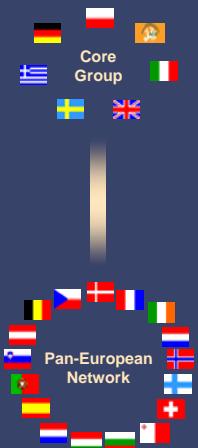




# Overview

- Objectives
- Aims
- Main research questions
- Methodology
- Findings
- Dissemination
- Results





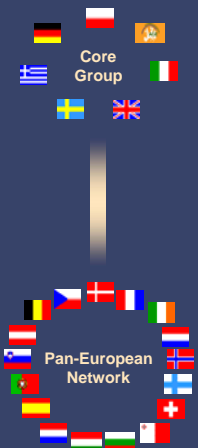
## Objectives (1)

- In all European countries increasing old-age is combined with more frequent and longer phases of being in **need of care**.
- The majority of all families in Europe will have to cope with the situation, that their ageing relatives will become dependent - often on **long-term-care** for several years.
- A European policy aim is to enable elderly people to remain **at home** as long as possible.
- But this is only feasible with adequate **support of family carers** as there is no realistic chance to cover these duties with other informal carers and professional carers only.



## Objectives (2)

- There is a need to arise the **awareness** to the care work done by family carers and their overall situation.
- Although family carers are the vast majority of all care-givers in total, most of them are neither **trained** in nursing nor have developed sufficient **coping skills**.
- The family carers of today are at **risk** of becoming those in need of care tomorrow.
- The need for European **research** in that field is evident – from an individual as well as from a societal perspective.





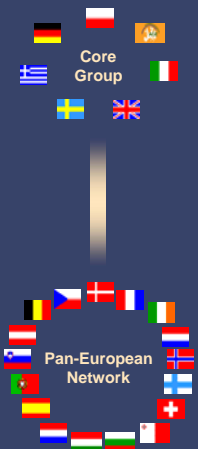
## Aims

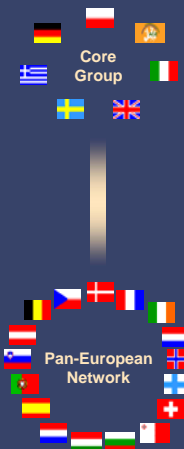
- EUROFAMCARE will provide a European review of the **situation of family carers of elderly people** in relation to the existence, familiarity, availability, use and acceptability of supporting services.
- EUROFAMCARE intends to push a **change management process** at various policy levels to promote social and health policies towards a **partnership approach** between family carers, professional providers and cared-for.



# Main research questions (1)

1. Which approaches and services already **exist** in the different European countries?
2. Which services are **used**?
3. Which services are able to promote **positive effects** and to avoid **negative consequences** and implications in caring for elderly family members?
4. What are family carers' **experiences** in using these?
5. What are the **barriers** and deficiencies that keep family carers from using support services?
6. Do these services **reach** the persons (family carers / older people) in need of support?





## Main research questions (2)

7. Do these services **fit** with the needs and demands of caregivers?
8. Which **characteristics of services** are considered to be important by care-givers and service providers?
9. Where can such services (measures) be **found**?
10. How can they be **implemented** and disseminated?
11. What services are (cost-) **effective**?
12. **Typology** of care situations?



# Methodology (1)

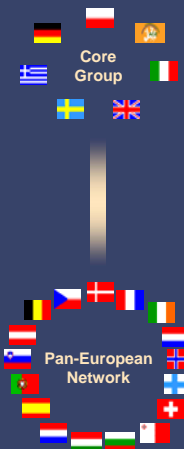
## Six Countries Comparative Study

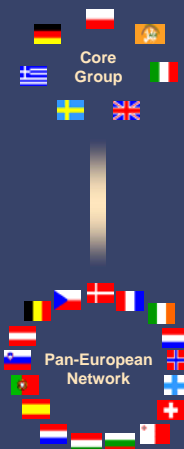
In-depth studies in the 6 countries (Germany, Greece, Italy, Poland, Sweden and UK) have been conducted using common guidelines for:

➤ **A baseline study with caregivers:**

Face to face interviews with 1.000 carers per country providing 4 or more hours of care/support per week to an elderly relative (65+);

The analysis of the interviews will (hopefully) lead to a better understanding about the relationship between perceived needs, usage and satisfaction of family carers in different care situations and services on offer.

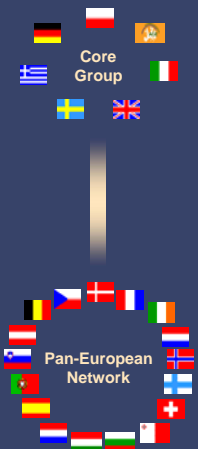




## Methodology (2)

### Six Countries Comparative Study

- **A 12-months follow-up study with carers to monitor main changes:** Face to face, phone or postal interviews  
  
The results of the Follow-up study will give information about changes in the situation of carers and their cared-for one year later. A socio-economic evaluation will calculate the economic consequences from perceived quality of life to European-wide politico-economic implications.
- **Service providers study:** Semi-structured interviews with 30-50 service providers per country  
  
The Providers study will add the providers view on services for carers and their cared-for based on semi-structured questionnaires.



## Methodology (3)

### Structure of Questionnaire: Baseline Study

- **Interview** context
- Caring situation and data on the cared-for
- **Elder's** need for support and care
- Elder's memory, behaviour and level of dependency
- Resources and restrictions of the cared-for regarding activities of daily life
- Characteristics about **caregiving** (e.g. time)
- Availability of substitution for caregiver
- Motivation of the caregiver to care for the relative
- Carers perception of the situation (burden, support)
- Carers perception of it own health and well-being
- Usage, needs and expectations regarding **support and services**
- Future **perspectives**
- Characteristics of the carer (e.g. education, gainfully employed)
- **Financial** aspects (expenditures, allowances, income, etc.)
- Space for comments on the issue



## Methodology (4)

### National Background Reports - NABAREs

Same structure in all 23 **NABARE** reports

1. Who are the family carers of elderly people?
2. How are care policies in the different countries designed and implemented?
3. What kind of health or social services supporting family carers already exist?
4. How does the financial support look like?
5. What are current and future trends in family care-giving?
6. Are there examples for good and innovative practice?
  - Reports are finished.
  - Publication of the **NABAREs** planned





## Methodology (5)

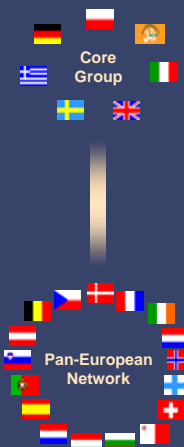
# Pan-European Background Report - PEUBARE

The pan-European synopsis **PEUBARE** contains the European situation of family carers'

- (non-)support,
- (non-)relief and
- (non-)expertise

in the years 2003/2004 with respect to the similarities between the countries as well as wide differences in service provision, state systems and cultures and the effects of all these factors on family carers and the older people they care for.

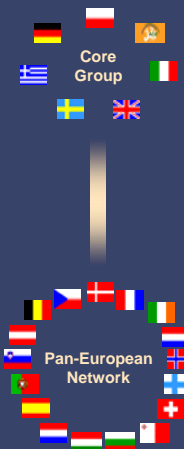
- Current policy trends are described.
- A draft version of **PEUBARE** is ready for discussion.





## Findings: PEUBARE (1)

- In most European countries round about 2/3 to 80% of the elderly in need of care are cared for by their relatives.
- Carers are mostly female.
- If carers are men, they are mostly spouses. **The percentage of male carers slowly increases in some countries.**
- In many countries family carers are not recognized neither by politicians nor by the public.
- In many countries family care is not on the political agenda, particularly in Eastern European countries.

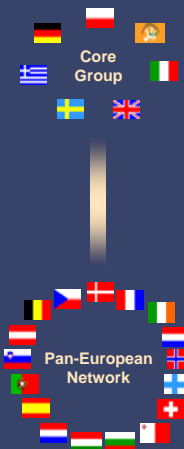




## Findings: PEUBARE (2)

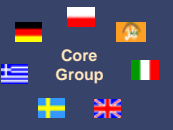
- There is a continued high **motivation** to care, but: a decreasing **potential** for family care (demographic changes).
- From studies in some countries we know:
  - Family carers are highly burdened.
  - They tend to overstress themselves.
  - They engage support or relief services too little or too late.
- Almost all reports are indicating the problem of **violence** in family care (from both sides). There is a lack of research on this hidden problem.





## Findings (Country examples): PEUBARE (3)

- **Alzheimer Societies** are active in nearly all countries
- **Sweden: 3 Year Action Plan 1999 – 2001** developing infrastructures of services for family carers
- **All, but especially Sweden and UK: respite care** for family carers (UK: right for all carers)
- **Germany: voluntary senior citizens companions**
- **Gerotechnology** under development
- Different steps to support **combination of working and caring**
- **Germany: Long-Term-Care-Insurance**
- **Sweden/UK: Health Promotion** for family carers









# Findings: Six Countries Study Baseline Questionnaire











# (1) Sociodemographics

							all
<b>Number of Carers</b>	<b>1014</b>	<b>990</b>	<b>995</b>	<b>921</b>	<b>1000</b>	<b>1003</b>	<b>5923</b>
ELDERS, women (%)	64,5	71,2	69,5	<b>57,7</b>	<b>72,8</b>	68,5	<b>67,5</b>
CARERS, women (%)	<b>80,9</b>	77,1	75,4	<b>72,0</b>	76,0	76,1	<b>76,3</b>
ELDERS' age (mean)	79,5	<b>82,0</b>	<b>78,0</b>	81,3	78,6	79,7	<b>79,8</b>
CARERS' age (mean)	51,7	53,4	54,5	<b>65,4</b>	<b>51,0</b>	53,8	<b>54,8</b>











## (2) Relationship to ELDER (% within country)

							all
child	55,4	<b>60,9</b>	<b>31,6</b>	40,5	51,1	53,4	<b>48,9</b>
spouse/partner	17,1	<b>10,9</b>	22,8	<b>48,1</b>	18,2	18,4	<b>22,2</b>
child-in-law	13,9	9,7	<b>15,3</b>	<b>4,5</b>	13,4	9,0	<b>11,0</b>
other	6,5	6,7	<b>19,5</b>	<b>2,8</b>	11,9	10,1	<b>9,7</b>
nephew/niece	4,2	<b>8,3</b>	4,6	<b>1,3</b>	3,0	2,8	<b>4,1</b>
sibling	1,8	2,4	<b>3,6</b>	1,8	<b>0,9</b>	3,0	<b>2,3</b>
uncle/aunt	1,0	<b>0,6</b>	1,5	0,9	<b>0,6</b>	<b>2,7</b>	<b>1,2</b>
cousin	0,1	0,5	<b>1,1</b>	<b>0,1</b>	0,9	0,7	<b>0,6</b>





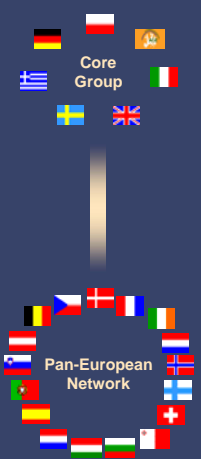
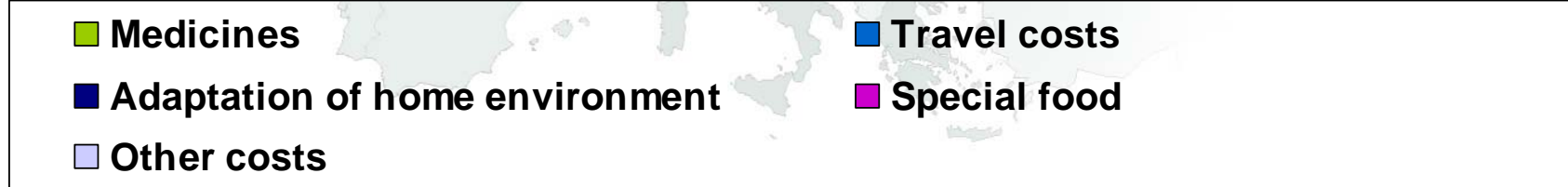
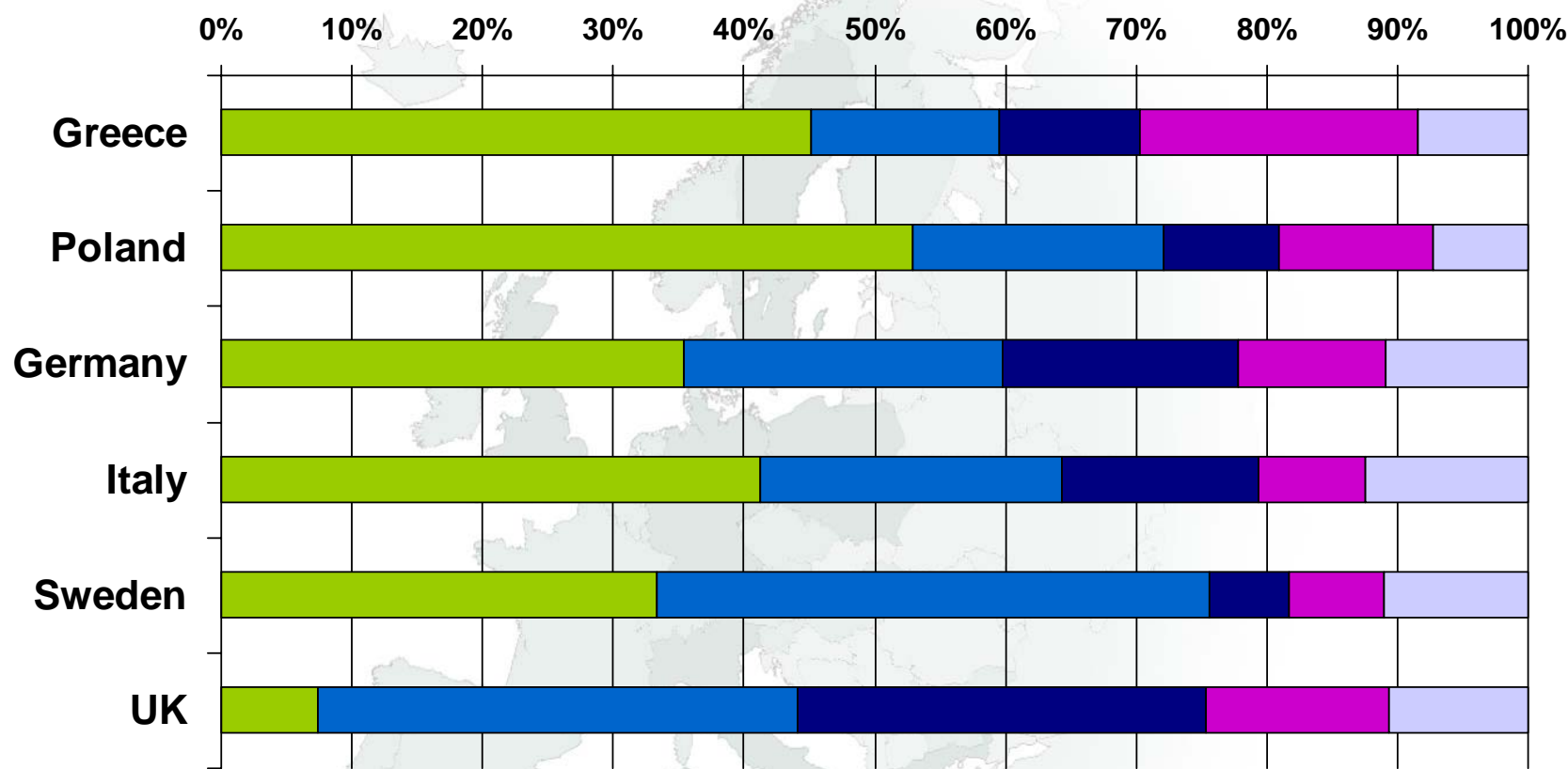
## (3) What factors influenced your decision to care for elder?

							all
<b>(1) emotional bonds (love, affection)</b>	96,8	96,3	90,5	96,6	94,1	92,6	94,5
<b>(2) a sense of duty</b>	89,3	73,3	79,5	67,7	91,6	85,8	81,4
<b>(3) personal sense of obligation toward elder as a family member</b>	91,4	57,4	75,6	73,6	93,7	90,9	80,6
<b>(4) caring for elder makes me feel good</b>	81,5	56,4	61,9	83,4	77,2	84,2	74,0
<b>(5) elder would not wish anyone else to care for them</b>	43,5	45,4	62,9	46,1	53,6	62,1	52,3
<b>(6) there was no alternative</b>	53,2	30,3	46,0	45,5	45,4	64,4	47,6
<b>(7) I found myself caring by chance without making a decision</b>	37,8	31,5	61,5	65,3	32,3	29,5	42,7
<b>(8) my religious beliefs</b>	40,0	38,0	22,6	8,2	67,7	24,7	33,9
<b>(9) cost of professional care too high</b>	43,8	31,1	30,2	14,8	34,4	45,1	33,5
<b>(10) economic benefits for both carer and elder</b>	8,0	4,3	8,7	13,2	8,1	12,3	9,1



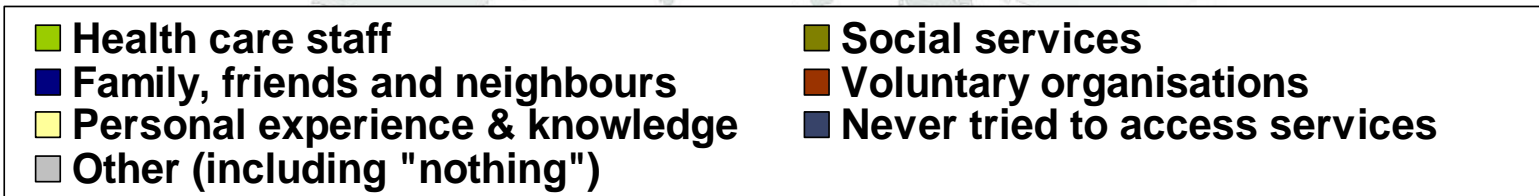
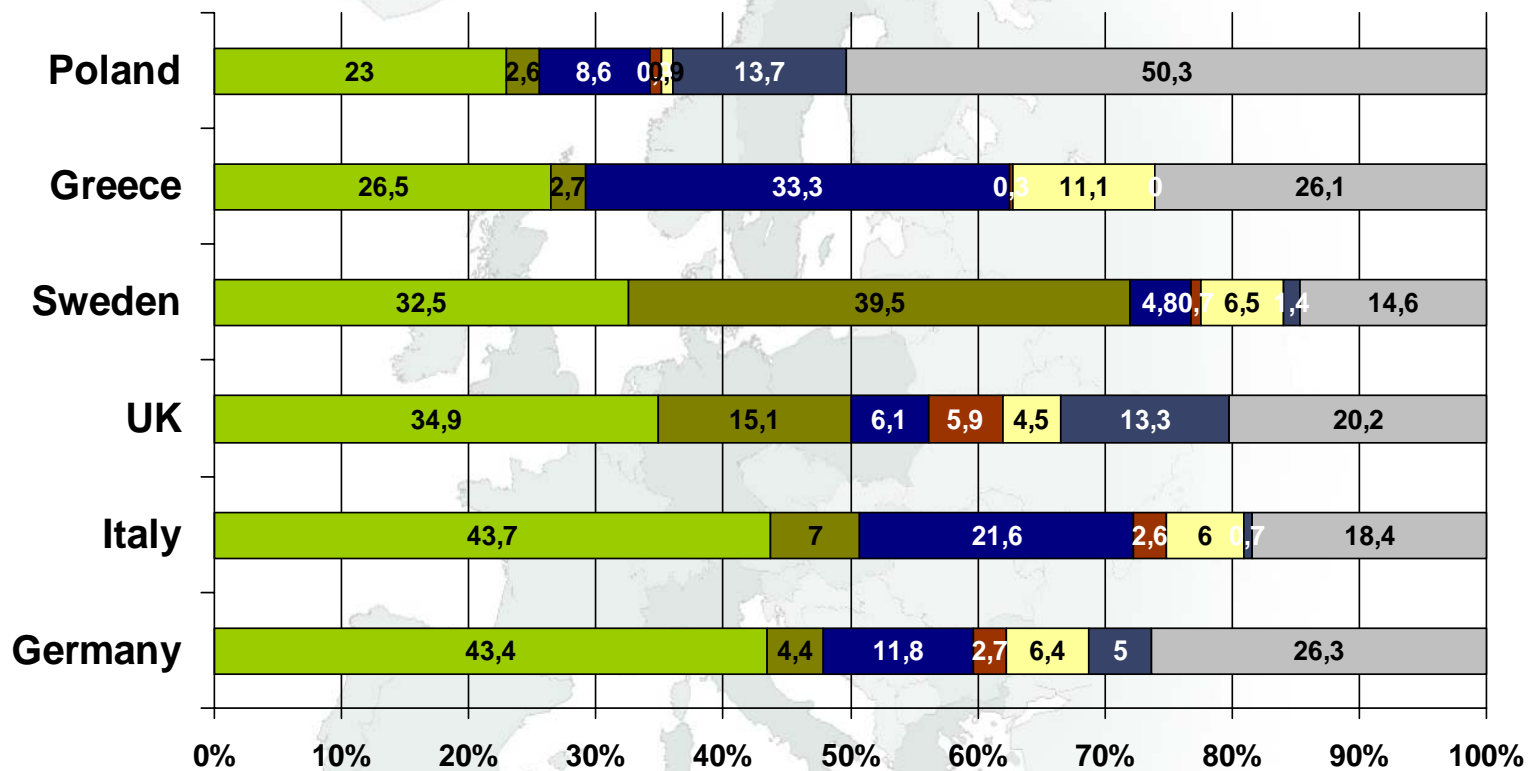
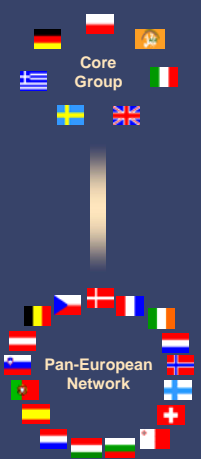


# (4) Has caring resulted in any additional financial costs?

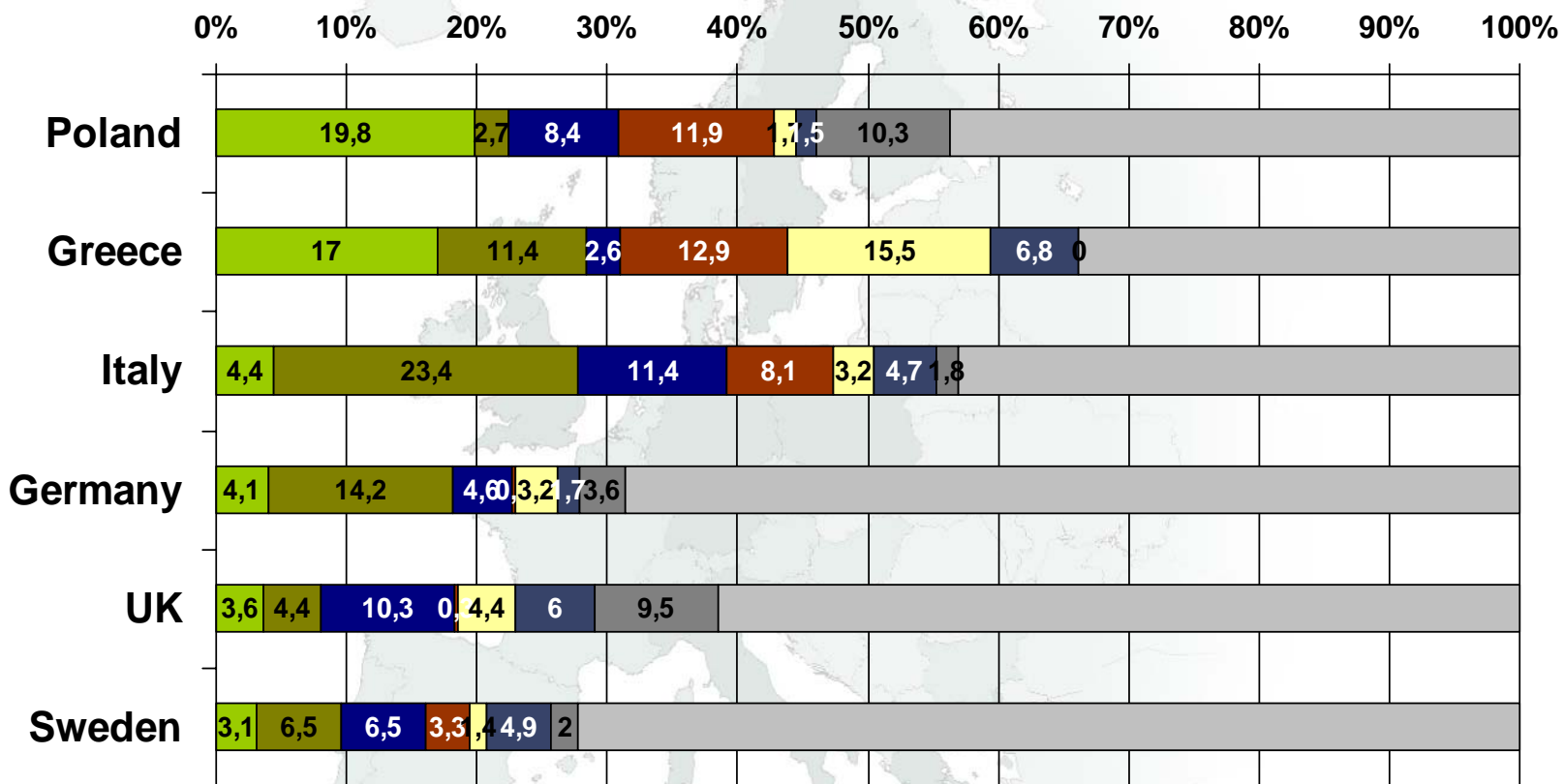




# (5) In your experience, who or what has been the **GREATEST HELP** in accessing services/support?



## (6) In your experience, who or what has caused the GREATEST DIFFICULTIES in accessing services/support?



High costs

Lack of information on services

Not accepted by OP

Never tried to access services

Bureaucratic/complicated procedures

Long waiting lists

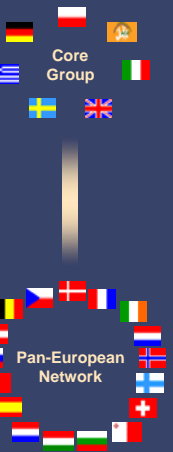
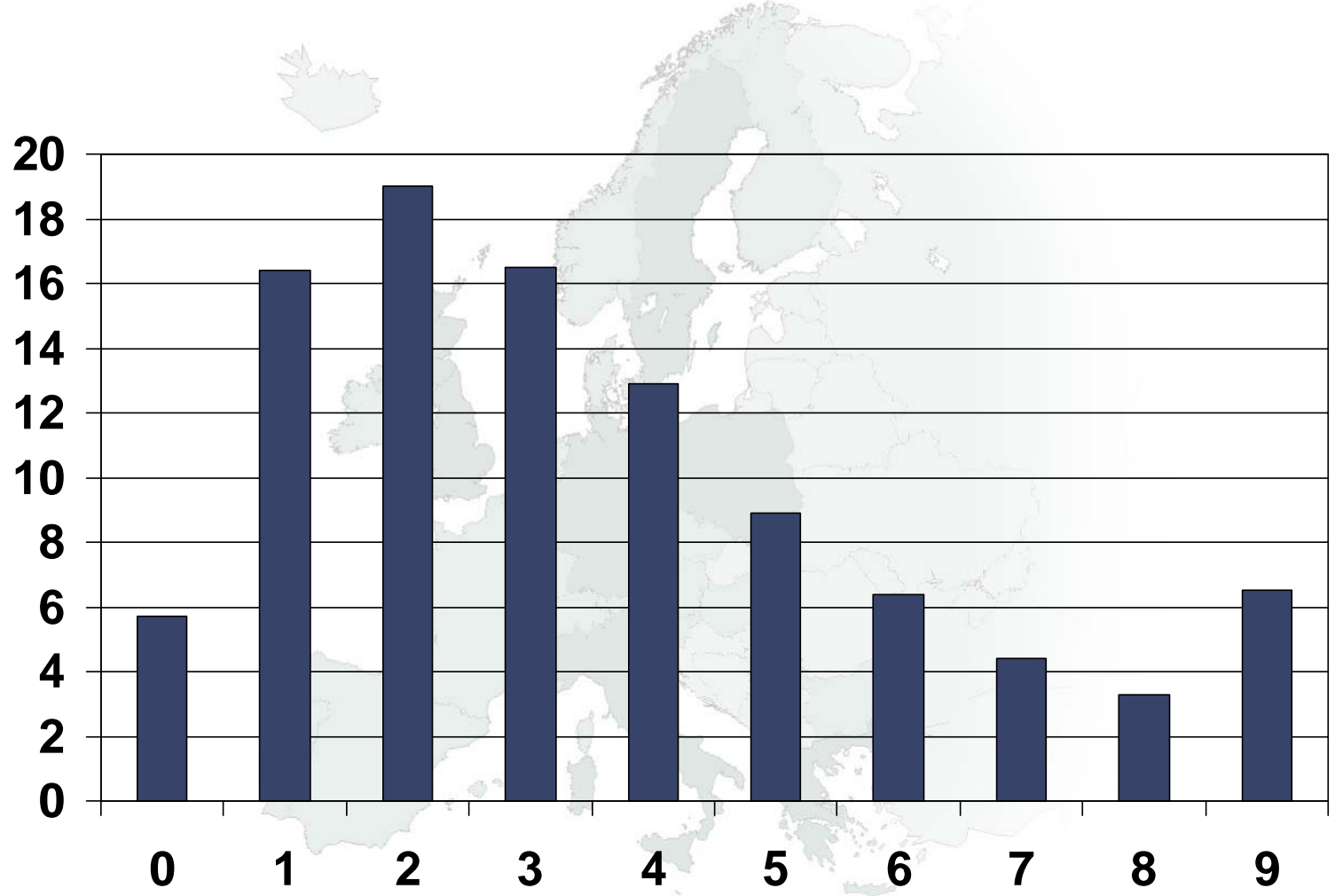
Poor quality of services

Other (including "nothing")



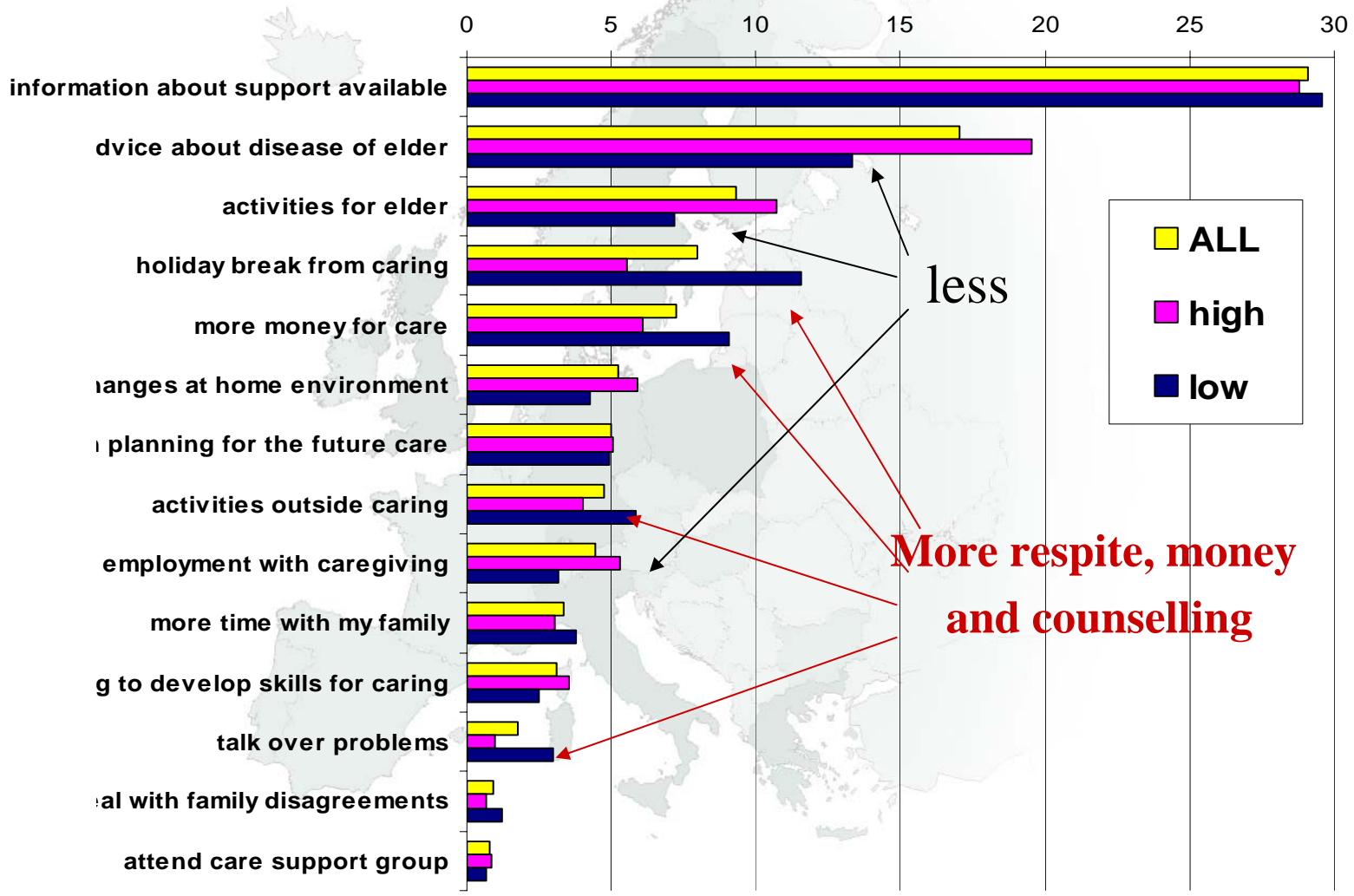


# (7) How many care services do OPs use? (%)



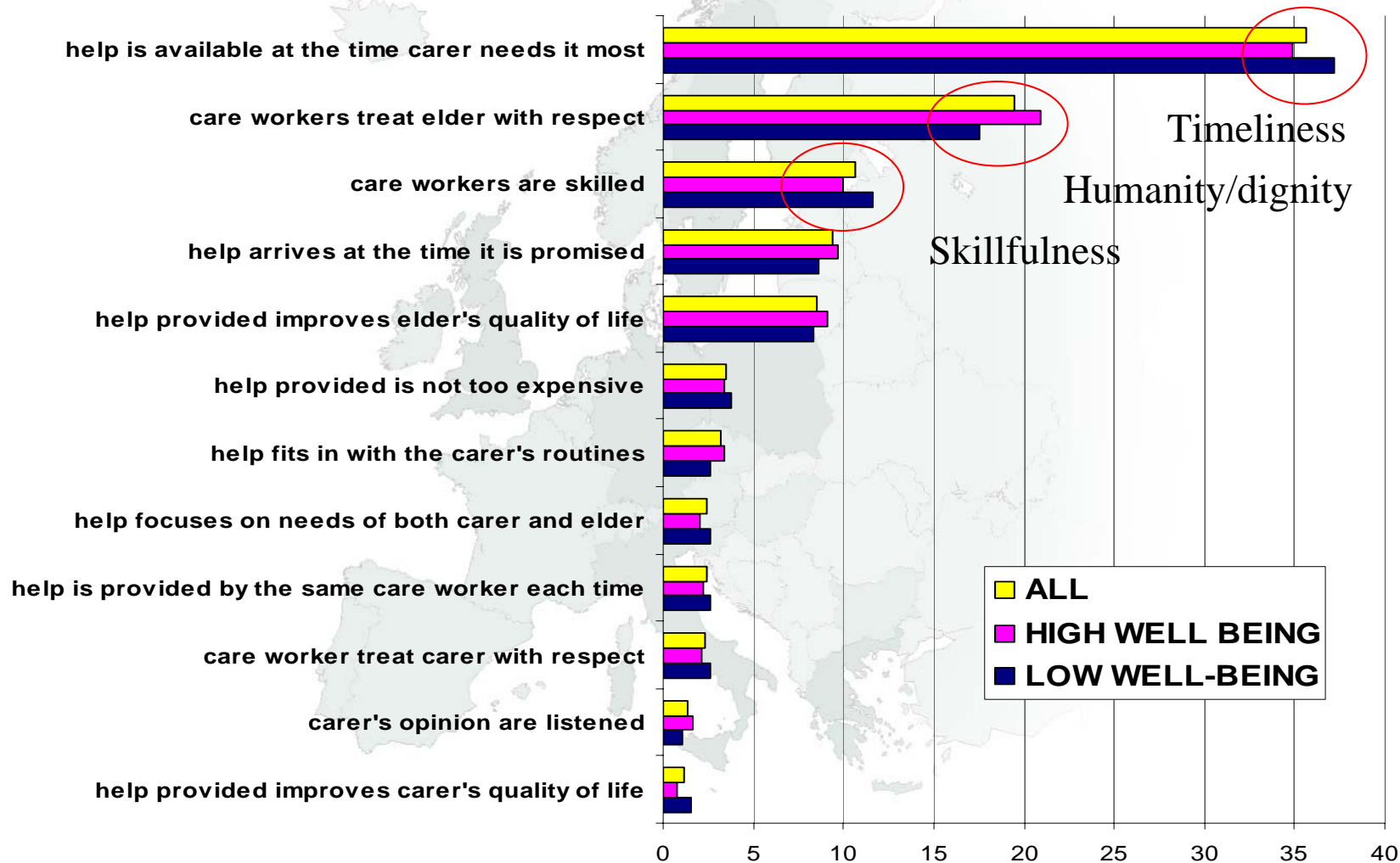


# (8) Which type of support would you rate as the most important to you?



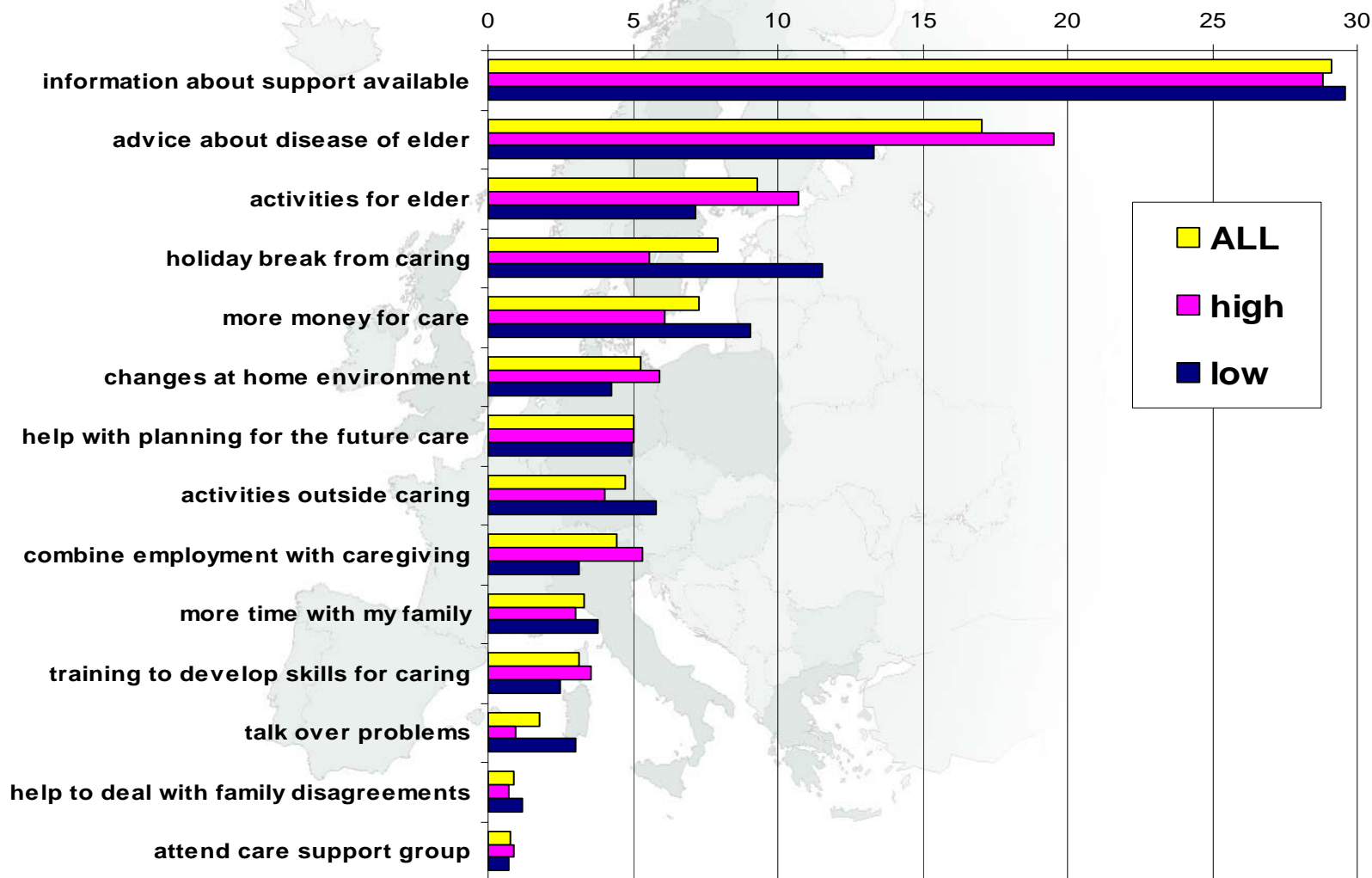


## (9) Which of the following characteristics would you rate as the most important to you?



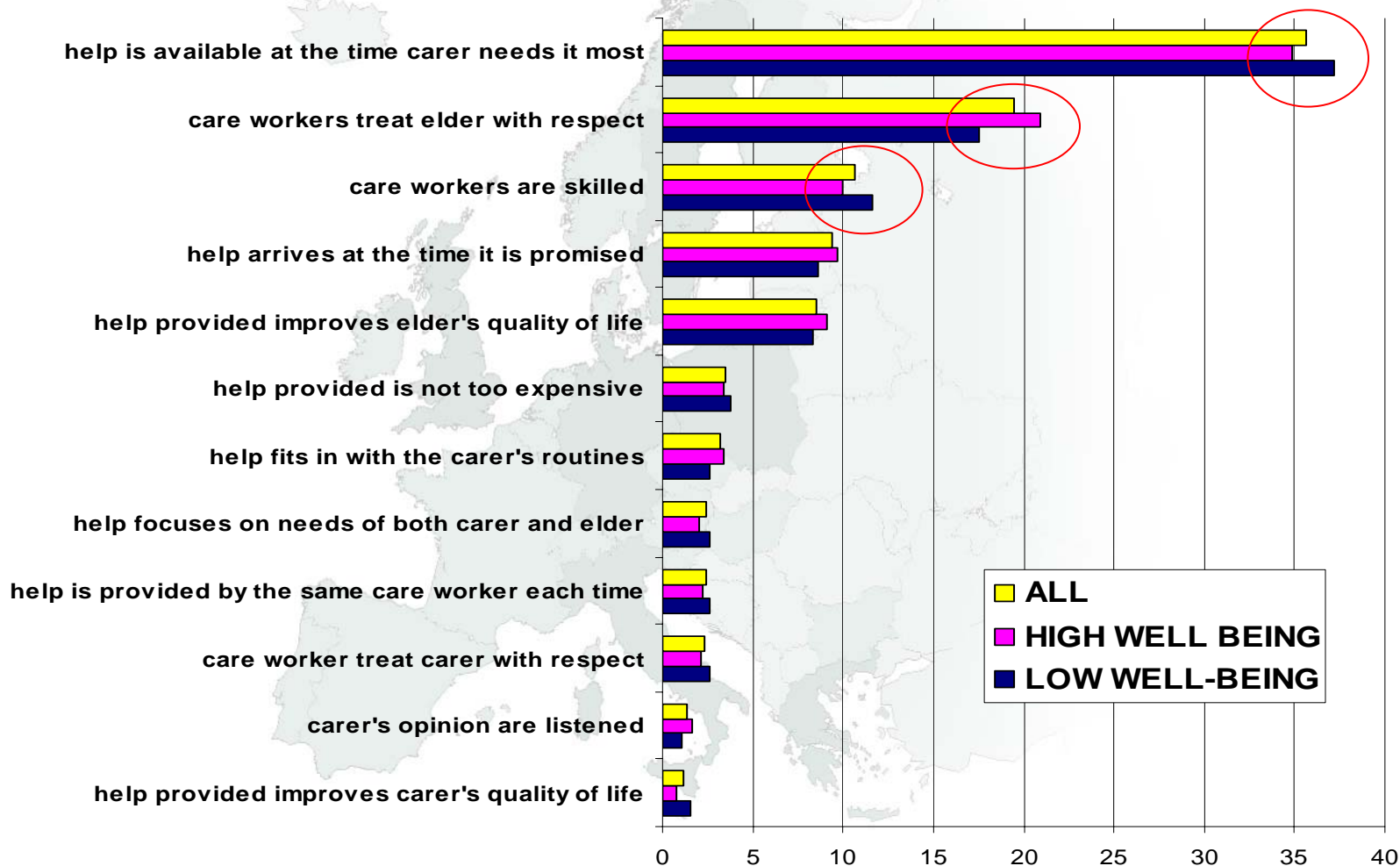


# (10) Which type of support is the most important? (%)



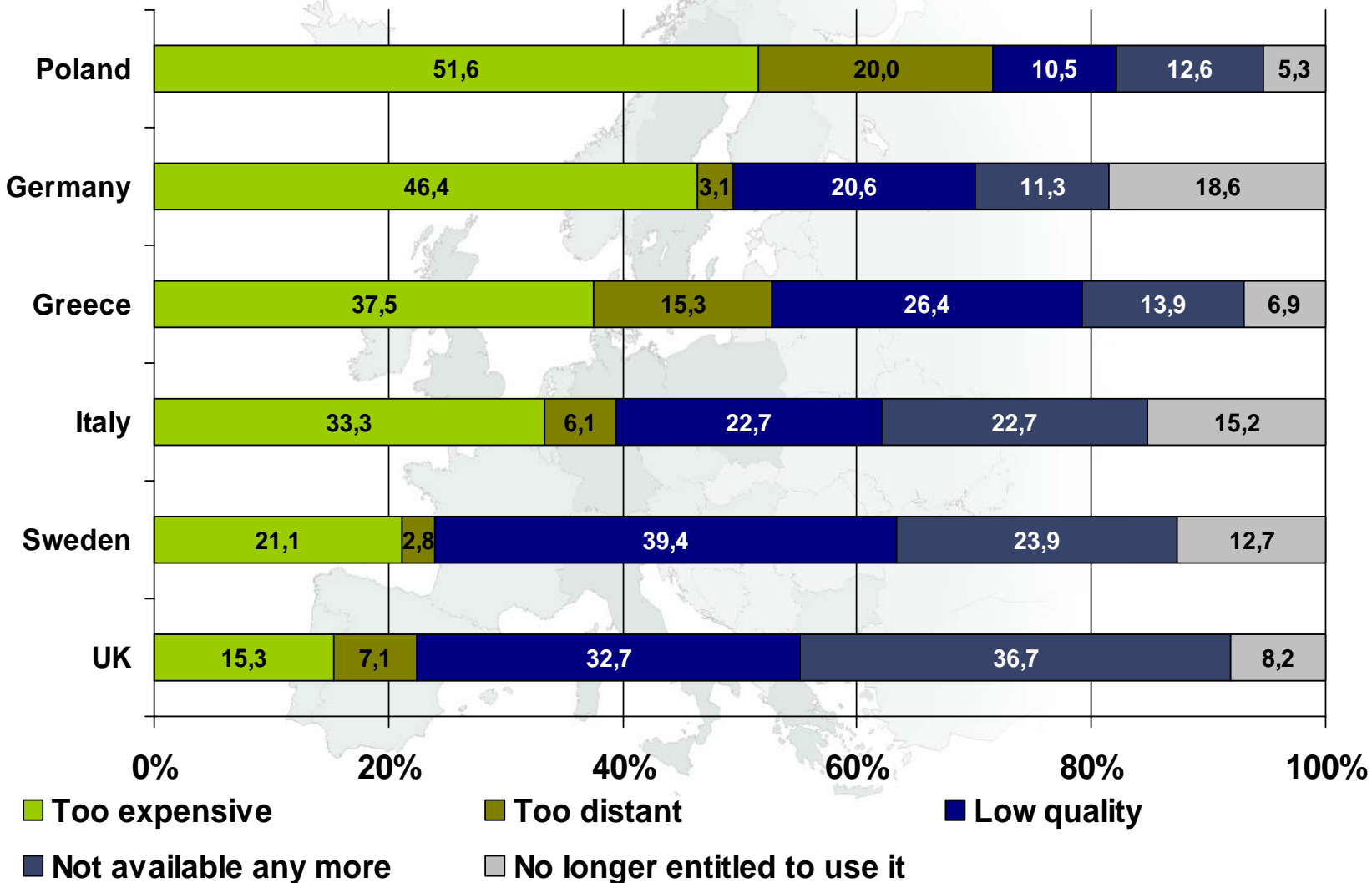


# (11) What is the most important characteristic of a service? (%)



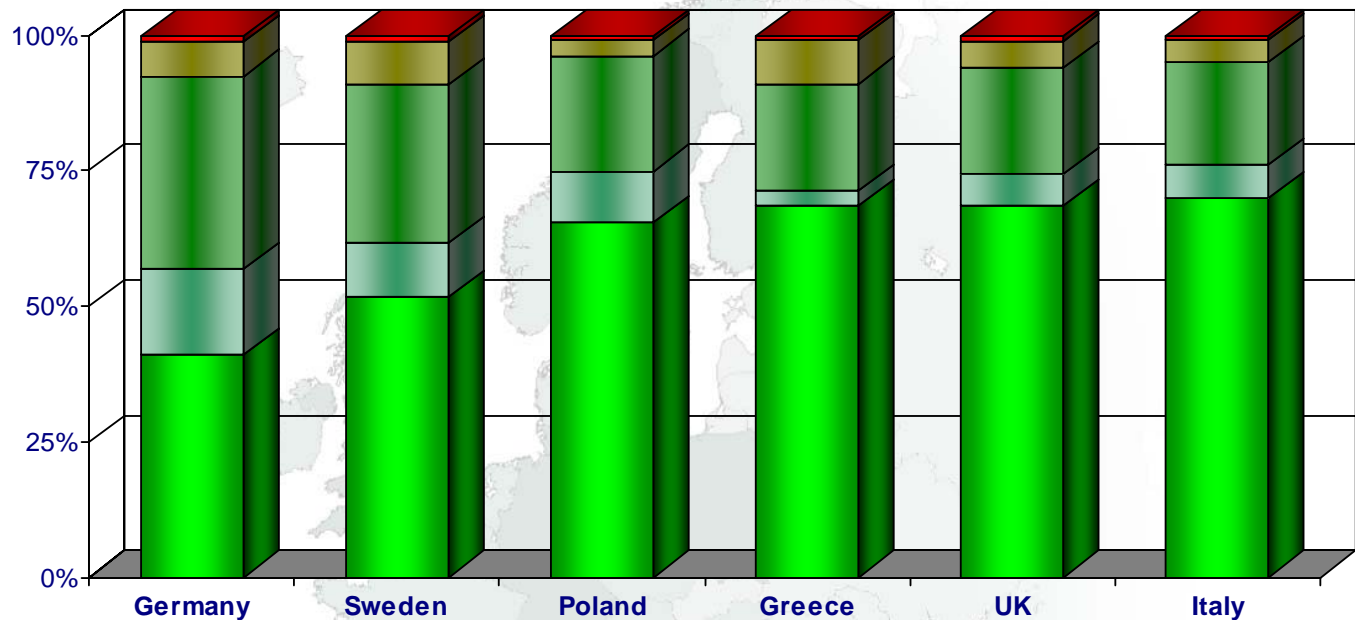


## (12) Reasons for stopping using needed services (n=723)

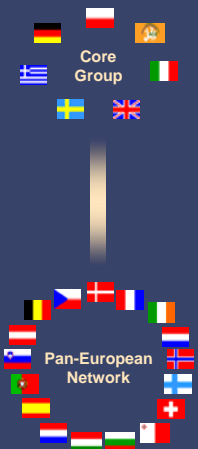




## (13) In the next year, are you willingly to continue to provide care to elder?

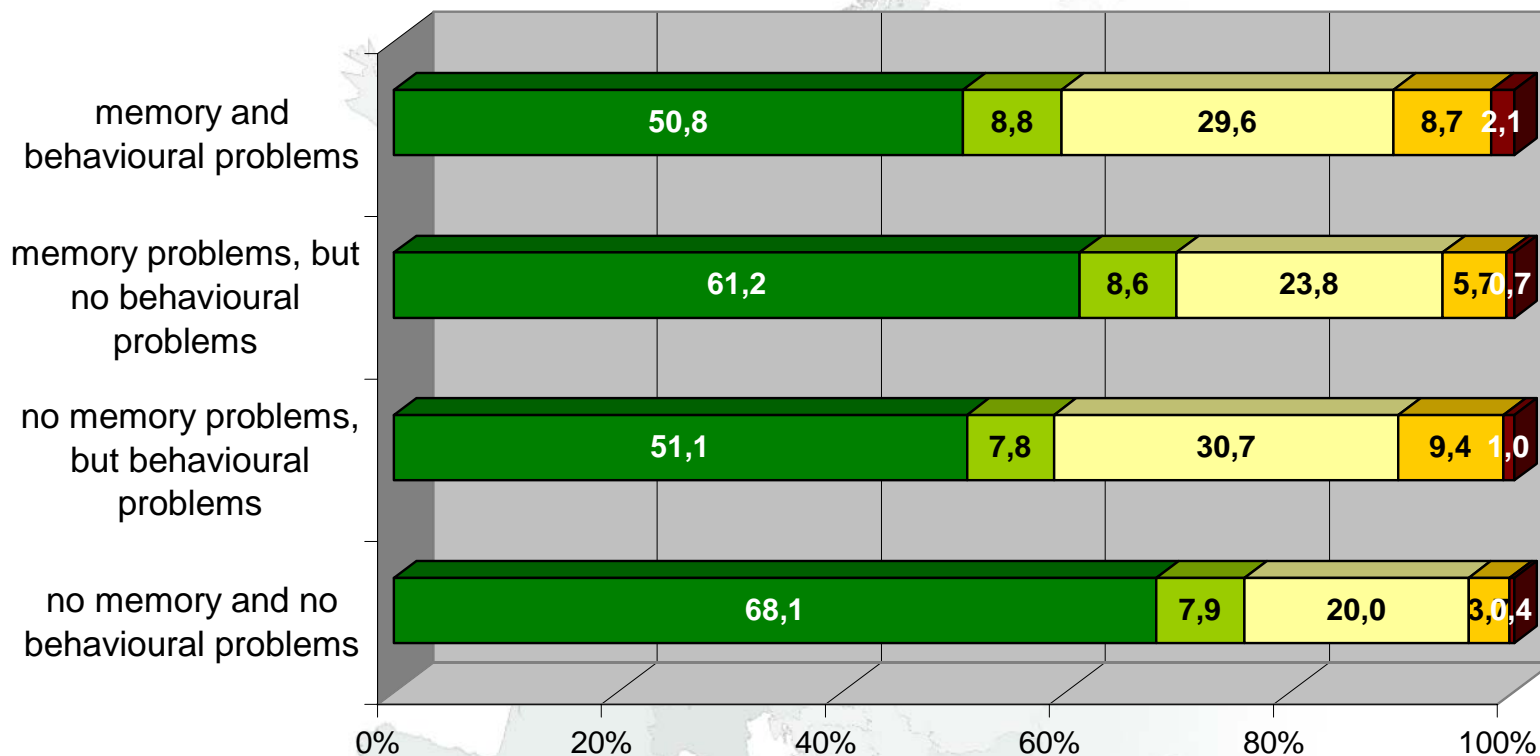


- No, I am not prepared to continue to provide care to ELDER, no matter what extra support I receive
- Yes, I am prepared to continue to provide care to ELDER but only if I have some more support
- Yes, I am prepared to continue to provide care if the situation remains the same
- Yes, and I would consider increasing the care I give for a limited time
- Yes, and I would even consider increasing the care I give if necessary





## (14) In the next year, are you willing to continue caring for the elder?

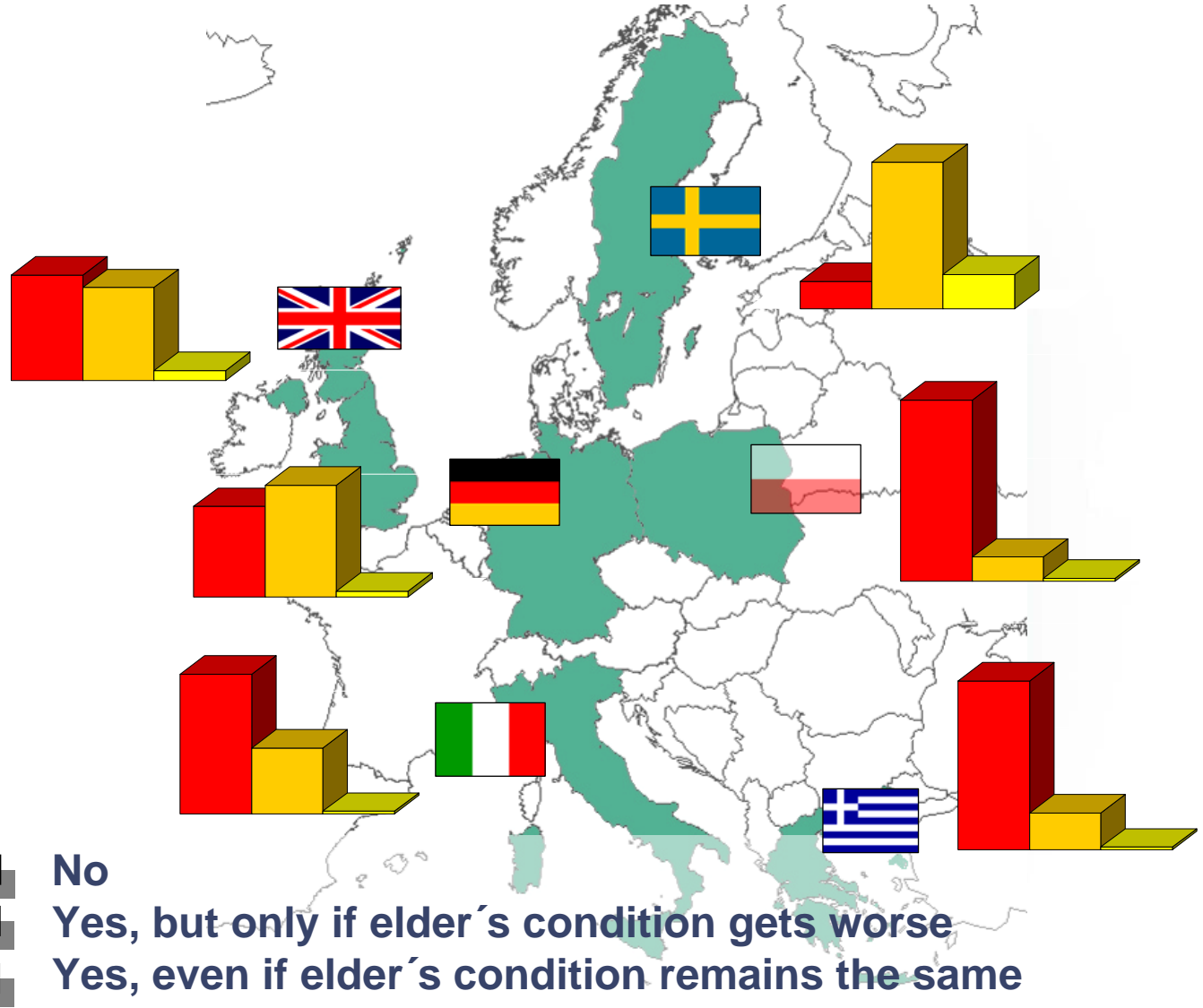
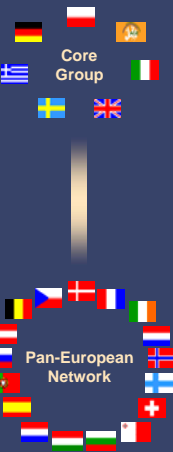


- yes, and I would even increase
- yes, and I would increase for a limited time
- yes, if the situation remains the same
- yes, but only with more support
- no, no matter what extra support I receive



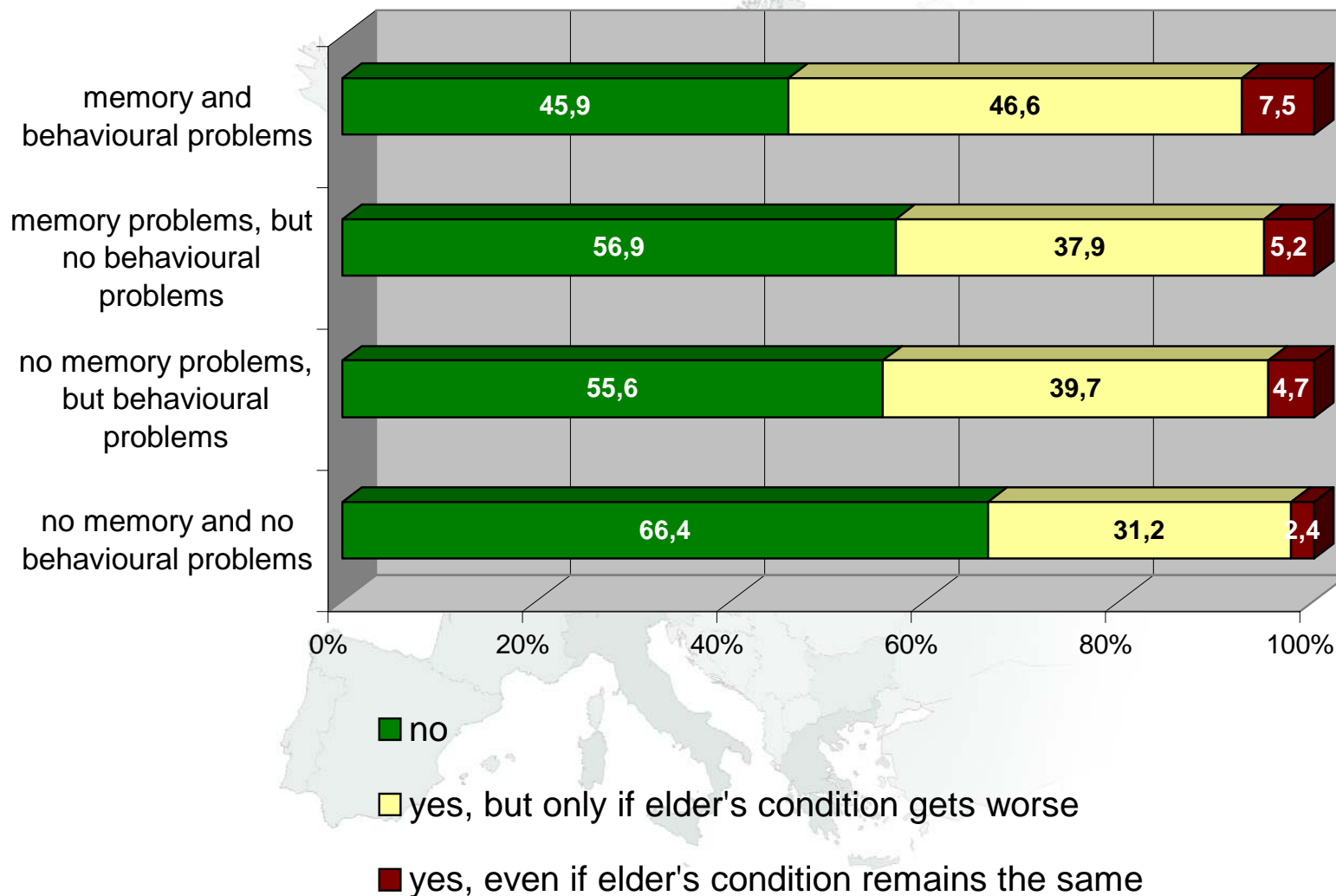


# (15) Would you be prepared to consider elder's placement in a care home?



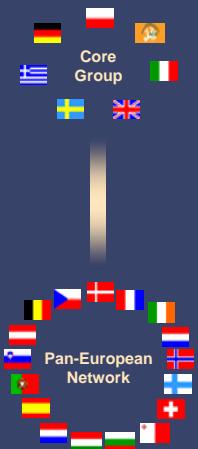
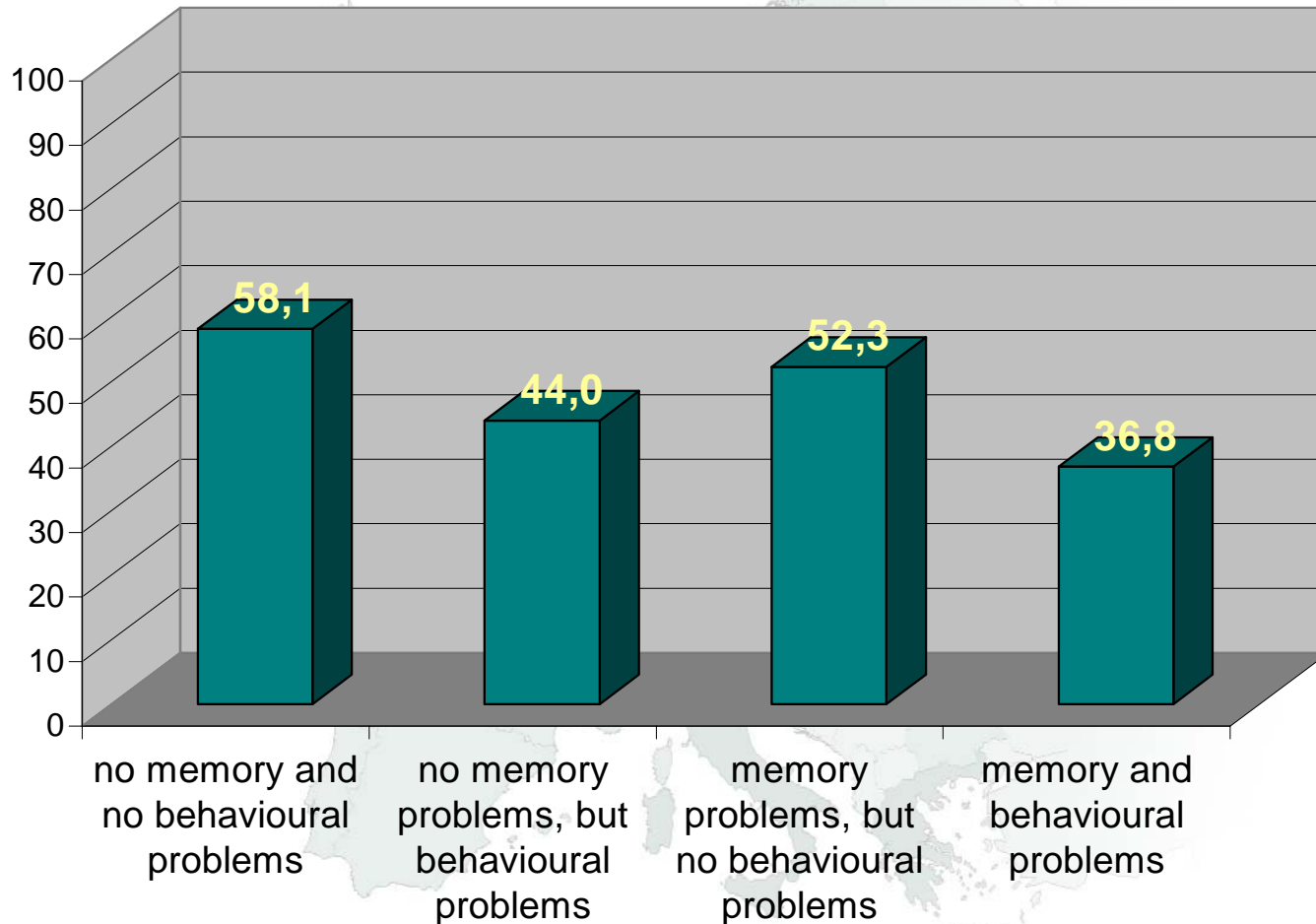
- No
- Yes, but only if elder's condition gets worse
- Yes, even if elder's condition remains the same

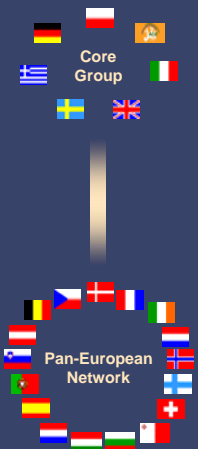
# (16) Would you be prepared to consider elder's placement in a care home?





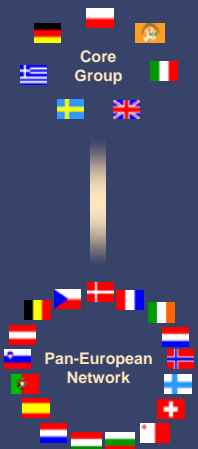
## (17) Quality of Life dichotomised: better quality of life in % (Overall question)





## Further Analysis (1)

- analysis related to **specific services** is required to provide useful insights for each single country
- **monetary transfers** (care payments and allowances) need to be taken into account to provide an integrated picture
- **cross-national variations in service use and preferences** reflect also cultural, legal and economic differences in the various types of welfare systems



## Further Analysis (2)

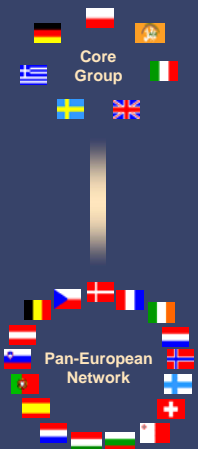
- in-depth analysis on **determinants of services use and impact** should control for co-existing effects exerted by relevant variables (such as carer's main socio-economic characteristics, dependency level of cared-for OP, strength of support networks, regional differences etc.)
- one-year **follow-up** and feed-back discussion with **service providers** will provide insights on how to improve the system.



# Dissemination (1)

Findings of the different studies undertaken in EUROFAMCARE will be broadly disseminated and discussed with different **target groups**:

- practitioners
- politicians,
- family carers





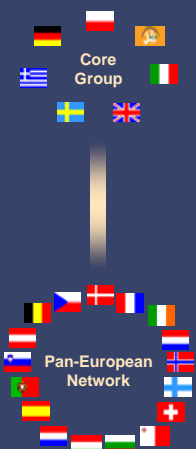
## Dissemination (2)

and

on different **political levels**:

- European
- National
- Regional
- Local

to understand better the gap between perceived needs and “political reality”, to contribute to an active change of attitudes and to support activities of change management.



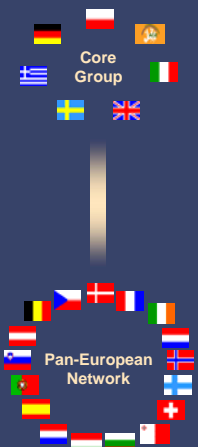


## Results (1)

The contribution of EUROFAMCARE to knowledge transfer in **practice, politics, science, media and public:**

- Lectures / publications / presentations
- **Information booklets** planned at national level to promote examples of good practice
  - for practitioners
  - for family carers





## Results (2)

- Development of a European network for the integration of science and practice:  
**EUROCARERS** - European umbrella organisation for the representation of the interests of informal carers (family, neighbours, friends , ...)
- Draft for a **European Carers' Charter**
- Concept for a **European Carers' Day**



# Final Conference of EUROFAMCARE on 18<sup>th</sup> November 2005 in Hamburg

**Thank you for your attention!**

**EUROFAMCARE website:**  
[www.uke.uni-hamburg.de/eurofamcare](http://www.uke.uni-hamburg.de/eurofamcare)