

Social representations of dementia: methods and conclusions of the research conducted in France

François Beck (head of the *surveys and statistical analysis*
department)

Christophe Léon (senior project leader – statistician)

Stéphanie Pin (head of the *population and lifecycle* unit)

The Alzheimer Plan

- **850,000 people** in France suffer Alzheimer's Disease and related disorders. This represents about **14% of people over 75 years old**.
- **The 2008-2012 Alzheimer Plan** in particular considers:
 - Increasing the ethical dimension of managing the disease,
 - Developing medical research,
 - Simplifying and improving the trajectory of the patient and of the family, in all of its dimensions,
 - Improving the management of early onset Alzheimer's Disease
- Measures Nos. 37 and S1 of the plan are designed to **“improve knowledge of the perception of the disease”**.



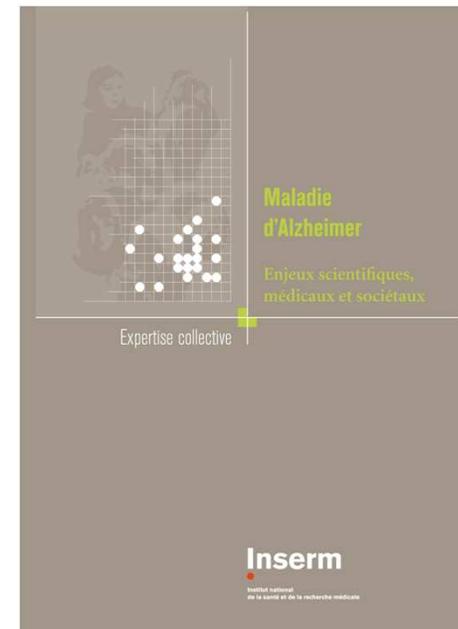
The social image of the disease

- **Postulate:**

- Alzheimer's Disease has a **negative social image...**

- Which may influence attitudes of families, professionals and society towards affected patients.

- Few studies are available on social beliefs about Alzheimer's disease (collective expertise report).



INPES instructed to run study

- The French National Institute for Prevention and Health Education (INPES):
 - Public organisation funded by the law of 4th March 2002 on patient rights and healthcare system quality,
 - Responsible for implementing health prevention and health education policies in the broader framework of the public health policy set by the government
 - Mandated amongst other things to develop expert knowledge and education on health and therapeutic education,
 - Involved in the previous national Alzheimer programmes.

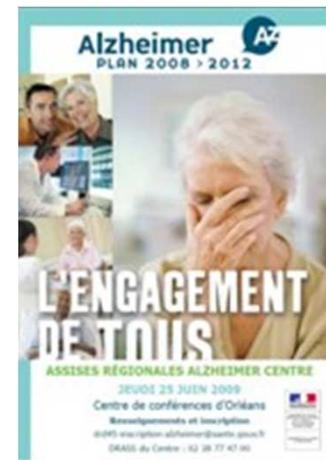
The Alzheimer's Opinion Survey (DEOMA) – Measures 37 and S1

“Understanding profane knowledge and attitudes of both the general public and health professionals about Alzheimer's Disease”

1. Improving **understanding of perceptions, knowledge and opinions** about Alzheimer's Disease (Measure 37):
 - In the general population,
 - In affected patients,
 - In family caregivers and in professionals (general practitioners, home workers and home assistants).

2. **Measuring their change over time** (monitoring the Alzheimer Plan) (Measure S1)

3. **Guiding actions:**
 - Research in human and social sciences,
 - Support,
 - Awareness and communication.



The Alzheimer's Opinion Survey (DEOMA) – Studies and surveys

Title of study	Study dates
1/ Literature review on social perceptions of AD	August 2008
2/ A qualitative study in the general population, family carers and health professionals	August 2008
3/ A survey of 2 000 18 year old and older people (general population)	December 2008
4/ A qualitative study in affected patients	February 2009
5/ A questions module in Baromètre MG (General Practitioners)	Field work finished January 2009 Results available 2011
6/ A survey in affected patients and family carers	March to October 2009 Results available in 2010
7/ A questions module in Baromètre Santé 2010	Field work finished 1 st September 2010 Results available 2011
8/ A survey in professional carers	September to December 2009 Results available 2010
9/ A qualitative study in professional home carers	Field work April and May 2010 Results available September 2010
10/ Reiteration of surveys 3 – 5 – 8	Mi-2012

Social perceptions of the disease 3

DEOMA surveys

- **General population survey:** attitudes and opinions of the general public towards Alzheimer's Disease
- **Family caregivers's survey:** perception and experience of Alzheimer's Disease by affected people and their close caregivers
- Survey in **professional home caregivers:** perception of Alzheimer's Disease and support and practices of professional home caregivers

Social perceptions of the disease – survey methods

The results are based on **3 surveys included in the DEOMA** using different methodologies :

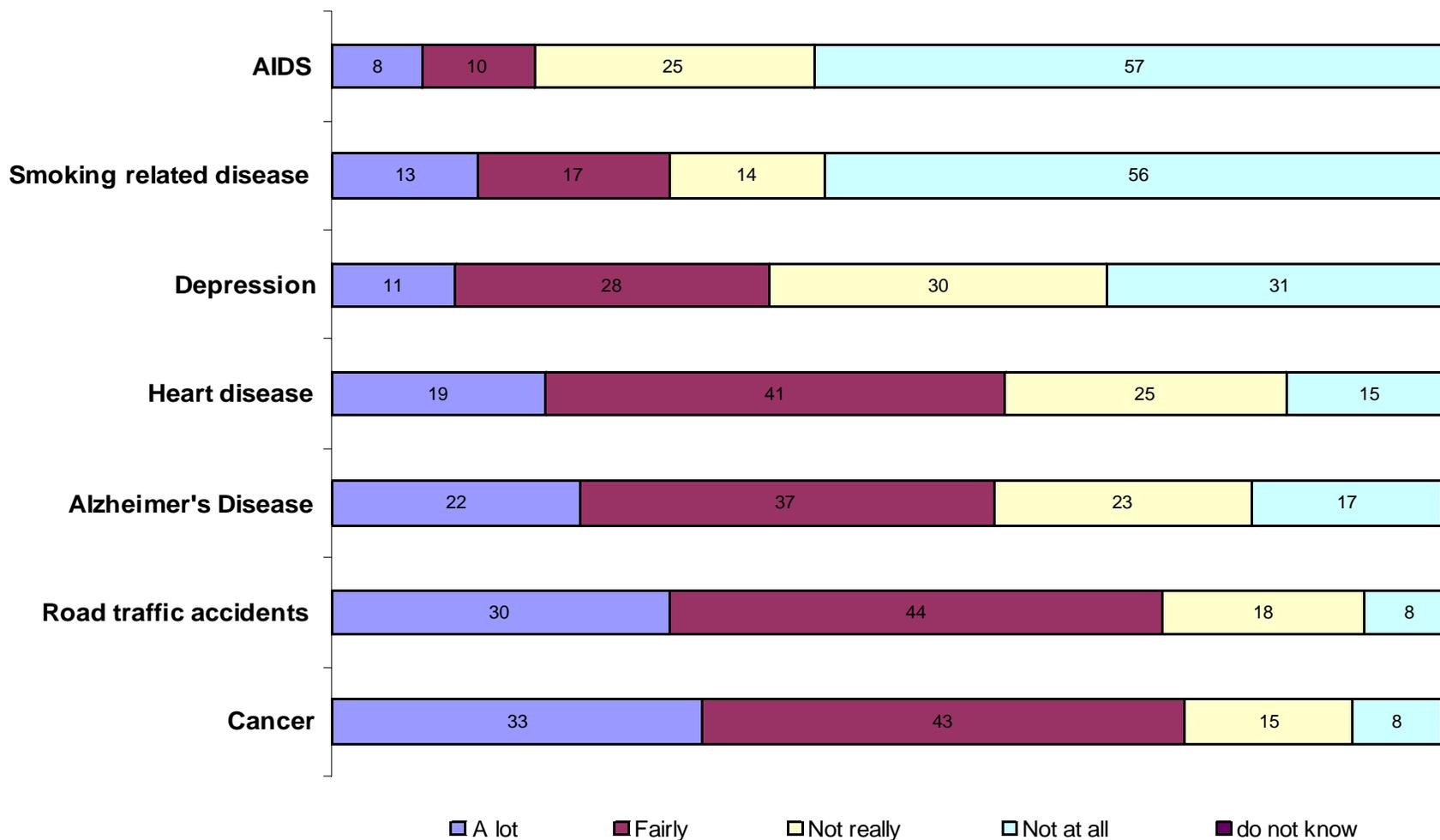
- A telephone survey in a representative sample of the national French population of 2,013 people aged 18 year olds and above, using quotas sampling,
- A face to face survey of people in 305 volunteer home caregivers (friends/family). People were identified from self-employed neurologists, memory consultation professionals, resource and research memory centres and by France Alzheimer,
- A survey in 1,213 home caregivers or home professionals recruited from 354 home care or help departments identified by quotas from the French National database of health and social organisations.

Social perceptions of the disease – Subjects examined

- Spontaneous perceptions of the disease (the 3 surveys)
- Opinions about the disease or available treatments (the 3 surveys)
- Level of information (the 3 surveys)
- Expectations of the government (the 3 surveys)
- Personal fear of the disease and feelings of being ill-at-ease with affected patients (general population)
- Feelings of exclusion and of managing to look after the friend's/relative's disease (family caregivers)
- Feelings of being able to improve the quality of life in affected people (professional caregivers)

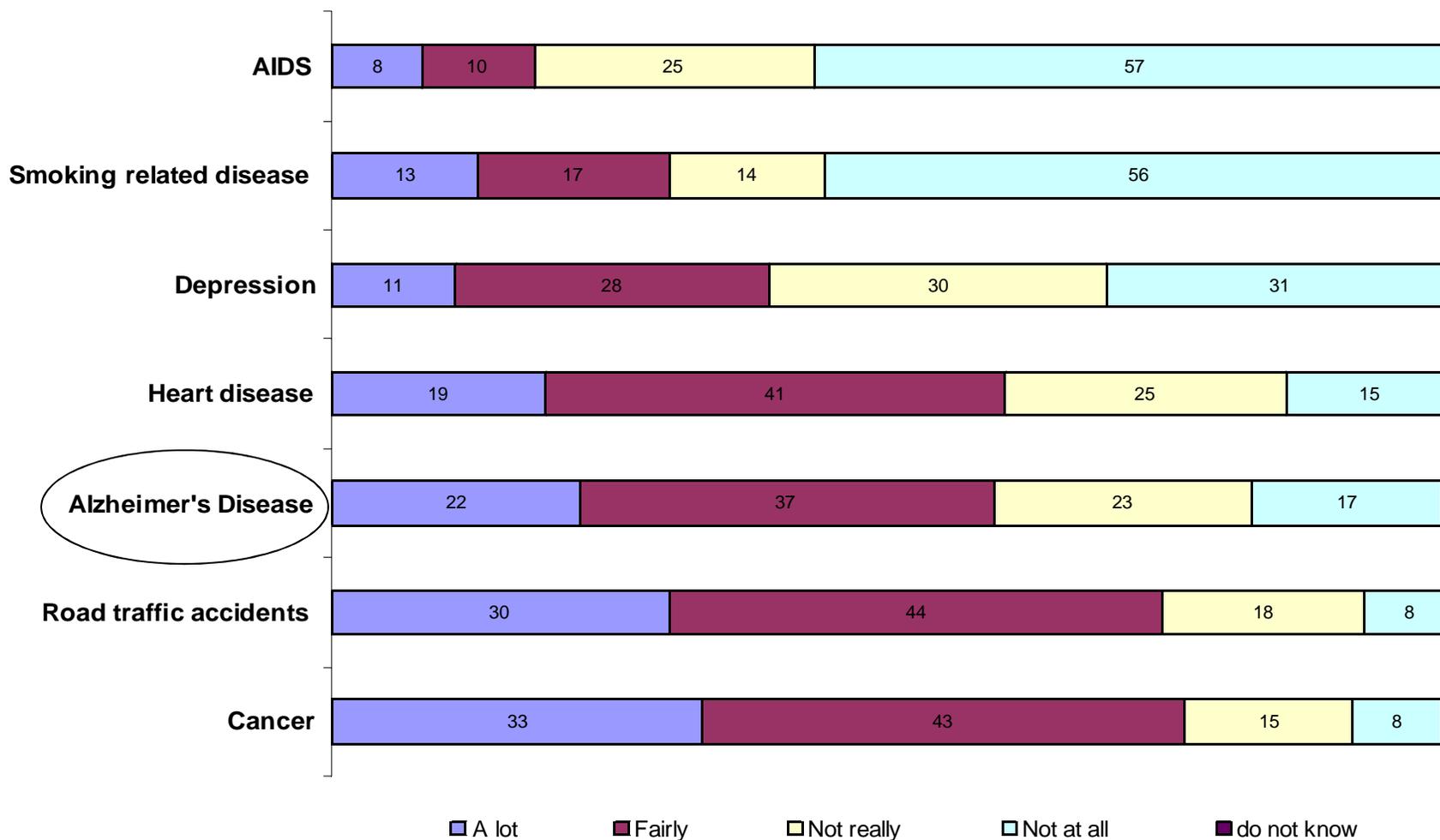
Social perceptions of the disease – Results

A personal fear of diseases or health problems in the general population



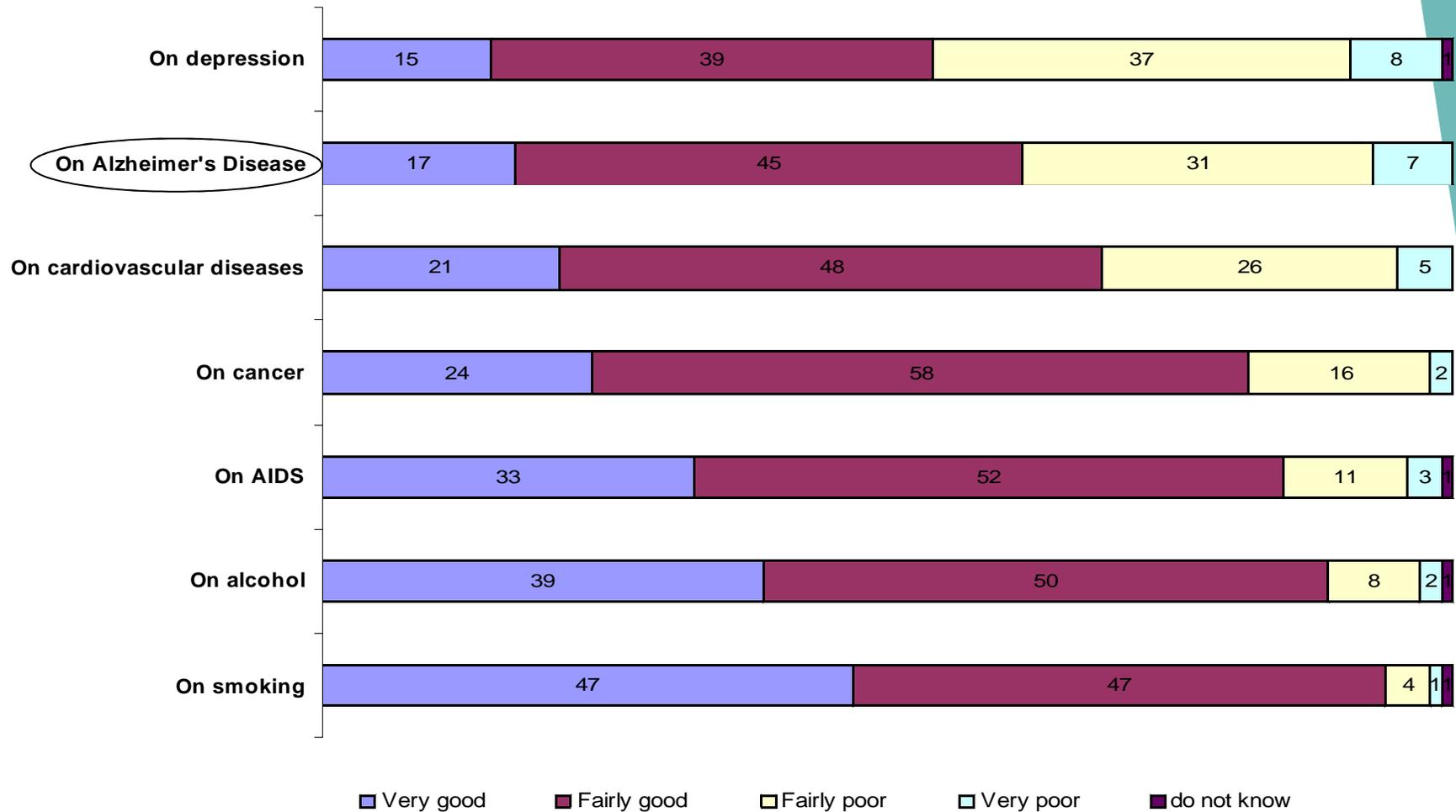
Social perceptions of the disease – Results

A personal fear of diseases or health problems in the general population



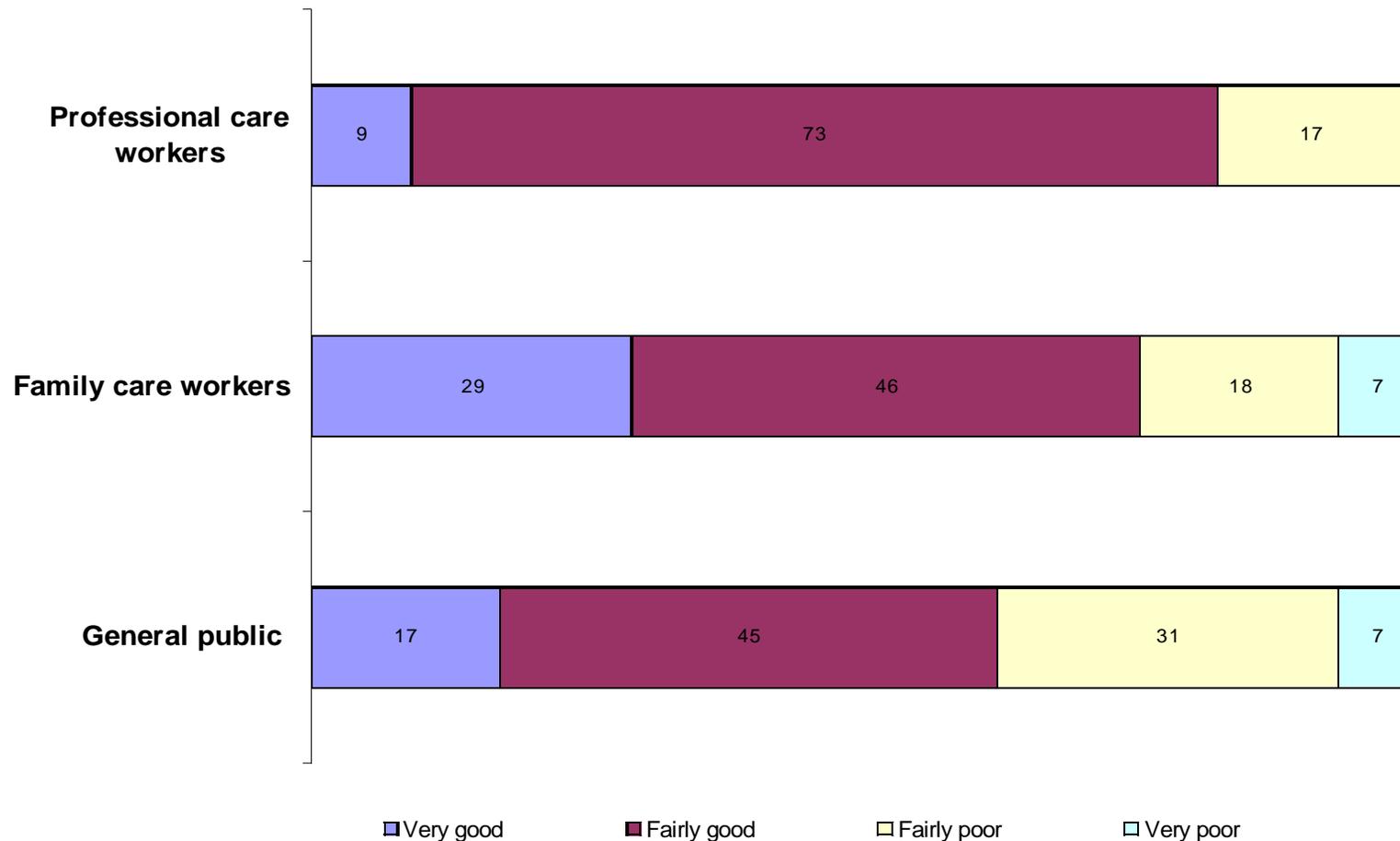
Social perceptions of the disease – Results

Feelings of being informed about the major health topics in the general population



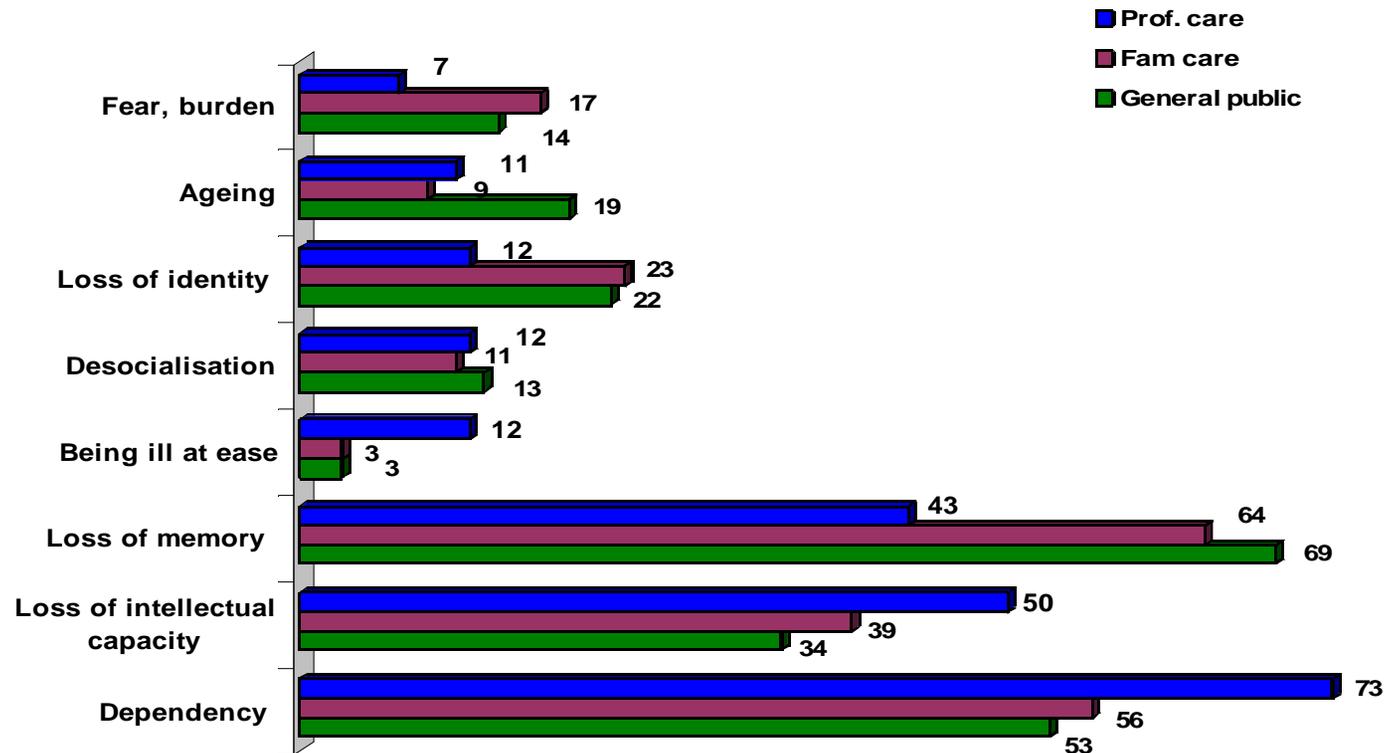
Social perceptions of the disease – Results

Feelings of being informed about Alzheimer's Disease in general depending on population questioned



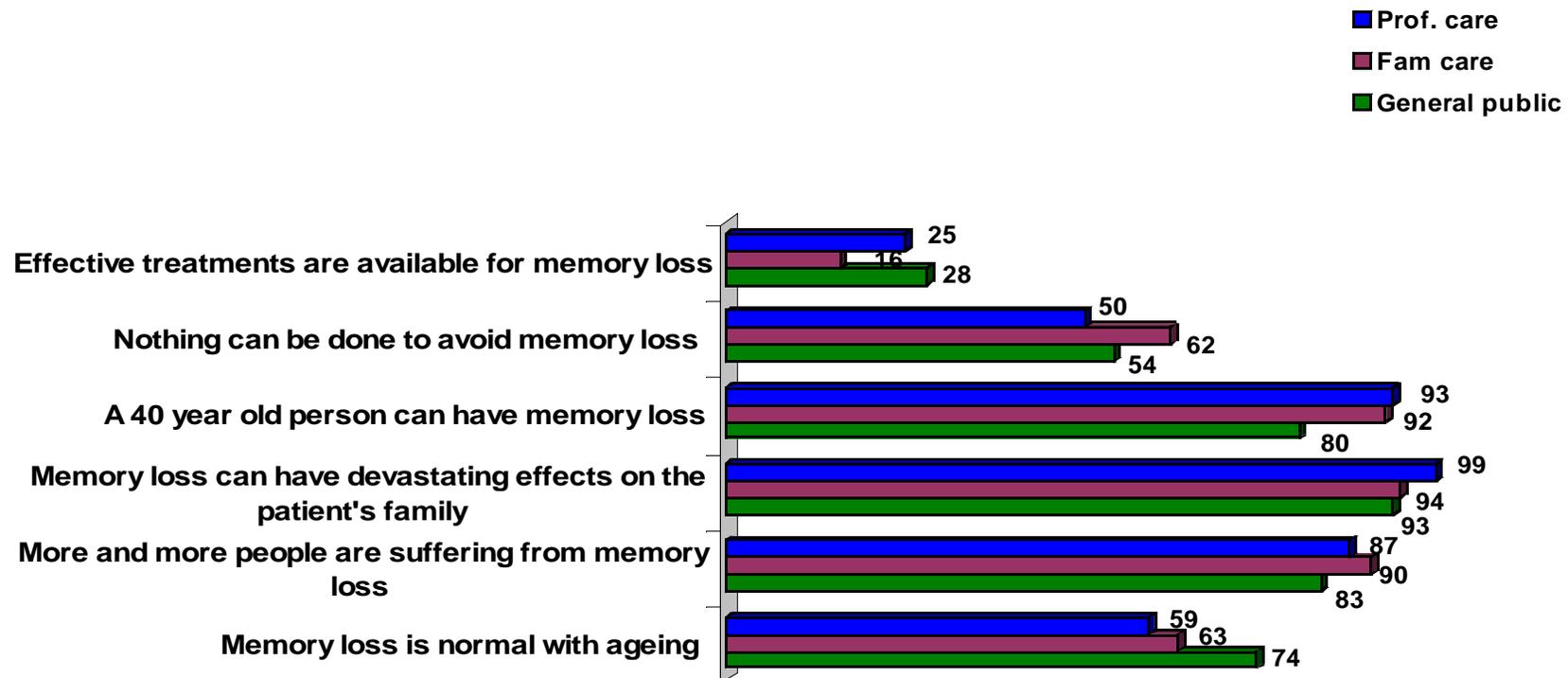
Social perceptions of the disease – Results

Words, ideas or images spontaneously associated with the term Alzheimer's Disease by population questioned



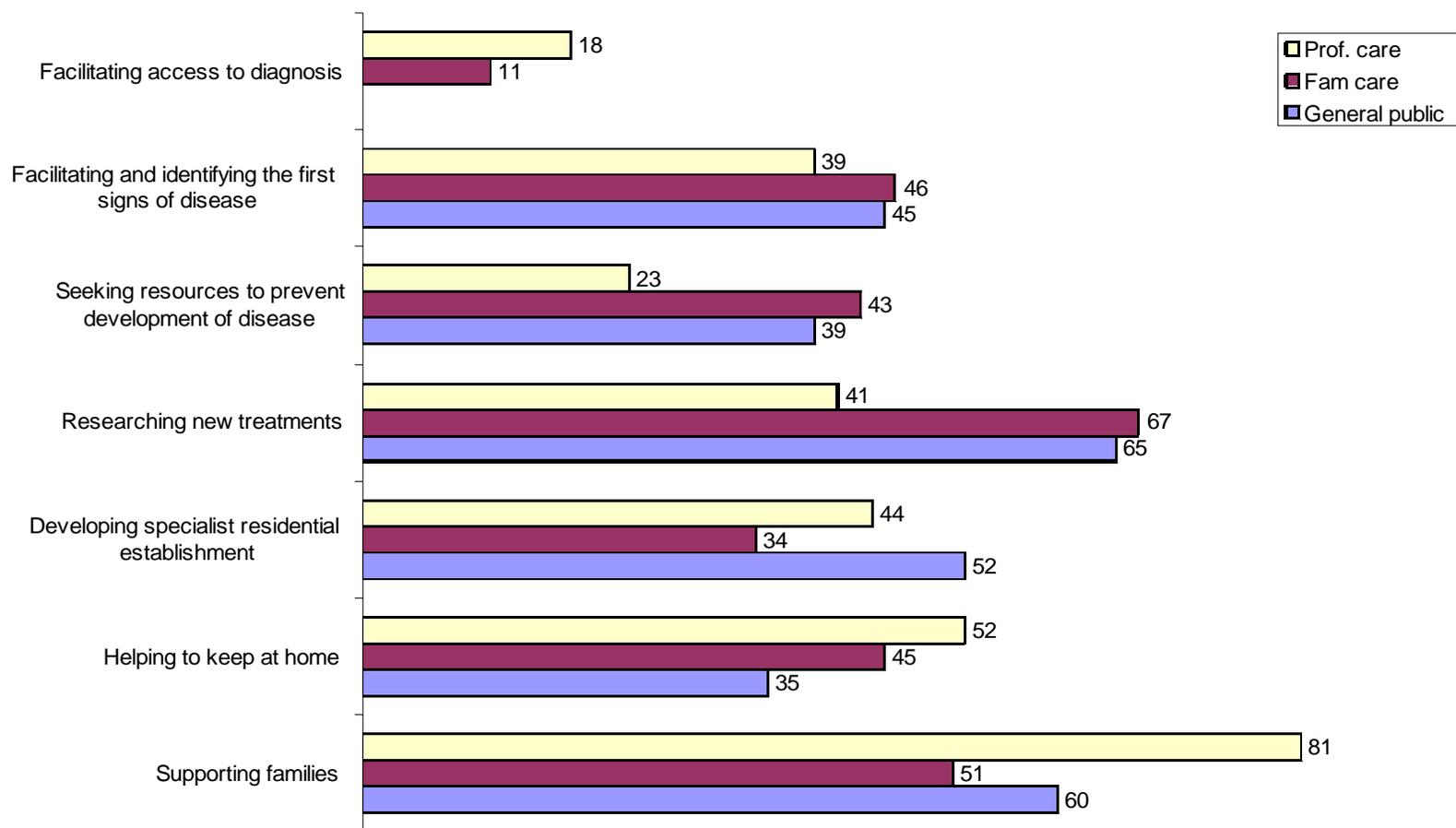
Social perceptions of the disease – Results

Opinions of Alzheimer's disease by population questioned



Social perceptions of the disease – Results

Objectives which should state priorities to combat Alzheimer's Disease by population questioned



A survey on dementia patients

- A pilot survey in Alzheimer affected persons (n=161) (march to october 2009):
 - Selected by general practionners or specialists and by the *France Alzheimer* association (inclusion criteria: **MMS \geq 18; Alzheimer diagnostic set and expressed by the practionner** ; ability to participate in a declarative survey; willingness to participate);
 - Interview at patient's home face-to-face with experienced and trained interviewers;
 - Most of the time in the presence of a close relative
- Subjectives perceptions mainly positive
 - Concerning their health: 77% of those patients consider in *rather* good health
 - Concerning their life in general: 85% of them are satisfied by their life in general, 65% by their physical health condition
 - Concerning the care they receive, even if about 40% find mediacal informations too complicated.
- Sadness and helpless are both the main patients' feelings regarding their disease (about 40% of them).
However several positive feelings are reported by patients: 33% amongst them evoke fighting spirit their diseaes inspire them, 21% declare they are optimistic.

Social perceptions of the disease – Conclusions

- **The image of the disease ranges from banal to gravity**
 - Consensus between populations on its major components: loss of memory, dependency, loss of cognitive capacity,
 - Simplistic use of the term “Alzheimer” to refer to mild forgetfulness,
 - Confusion between AD and normal ageing in the general public,
 - Feelings of fear and helplessness about AD,
 - References to advanced stages of the disease to the detriment of early or moderate disease stages.

Social perceptions of the disease – Conclusions

- **Relocate the affected person at the centre of attention**
 - AD is perceived as the disease mostly affecting friends and family,
 - A degree of rejection of the affected patient,
 - Severe distress for the affected person and his friends and family shared by the general public and ,
 - Feeling of uneasiness in the general public which may lead to stigmatisation.

Social perceptions of the disease – Conclusions

- **High expectations from research**
- **Needs of support, more difficult to assess:**
 - Flexibility in aids and services for the close relatives
 - Simpler information and better involvement in patient decisions,
 - Training and coordination for professional caregivers,
 - Training in giving the diagnosis and non-pharmacological treatment for GPs

Social perceptions of the disease – Discussion

- **These results argue for initiatives being developed to combat the stigmatisation of sufferers and those close to them:**
 - By paying more attention to the early or moderate stages of the disease
 - By changing the perceptions of old age and ageing
- **Future**
 - Secondary analysis of DEOMA surveys,
 - Surveys repeated in 2012,
 - Publications in english

Publications

- Pin-Le Corre S., Benchiker S., David M. et al. Perception sociale de la maladie d'Alzheimer : les multiples facettes de l'oubli. *Gérontologie et société*, 2009, n°128-129 : p.75-88.
- Scodellaro C., Pin-Le Corre S., Deroche C. Représentations sociales de la maladie d'Alzheimer : une revue de la littérature. *Actualité et dossier en santé publique*, 2008, n°65 : p. 36-38.
- Evolutions 21 - Sept 2010 - Regards croisés sur la maladie d'Alzheimer : perceptions, opinions et attitudes du grand public, des aidants proches et des aidants professionnels
<http://www.inpes.sante.fr/CFESBases/catalogue/pdf/1318.pdf>
- Evolutions 22 - Sept 2010 - L'accompagnement de la maladie d'Alzheimer au domicile : perceptions et pratiques des professionnels du soin et de l'aide
<http://www.inpes.sante.fr/CFESBases/catalogue/pdf/1317.pdf>
- D'autres documents sont en ligne et téléchargeables gratuitement sur le site de l'Institut national de prévention et d'éducation pour la santé : *[ww.inpes.sante.fr](http://www.inpes.sante.fr)*

Thank you for your attention