Alzheimer’s Disease Opinion Survey Scheme (DEOMA)

Perception of Alzheimer's disease by professionals working in home assistance and care units (AidProf Survey)

I. Background

According to CNAMTS (2007) data, 400,000 people over 60 years of age (all schemes) were diagnosed with a long-term illness (LTI) and/or were undergoing treatment for Alzheimer’s or a related disease in 2007. Based on this, the prevalence rate for the entire over-60s population is 2.7%. This figure rises sharply after 75 years of age, however, exceeding 14% by the age of 90. These figures are lower than those typically put forward by epidemiologists. Studies on samples from the general population, based on systematic research on the disease using specific tests, have estimated that 850,000 people are suffering from Alzheimer’s disease in France, half of whom are likely not to have been diagnosed or reported.

The system in France for keeping and caring for the elderly in their own homes is currently developing in various forms, giving rise to an increase in the different types of support available.

There are four challenges influencing the success of the provision of care at home:

- community health support provided by specialist units
- adaptation of accommodation
- provision of trained staff
- provision of respite care options for carers.

According to the HID (handicap, disability and dependence) survey, in terms of formal care, 70% of providers working with the elderly are home helps (housekeepers and care workers).

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1 Study on Alzheimer's Disease - Health Insurance - Press release of 23 October 2008
and 27% are paramedical professionals; social workers (case workers, educators etc.) only make up 3% of professional carers (Joël, 2003).

As part of the third strategic area of the 2008-2010 Alzheimer’s Plan, entitled "taking action on a social issue", Measure No. 37 is aimed at improving "knowledge of the perception of the disease". This task was assigned to INPES, which, since summer 2008, has set up an **Alzheimer’s Disease Opinion Survey Scheme (DEOMA)** among different sections of the population (general public, GPs, professional homecare assistants, patients and family carers).

Early studies carried out as part of DEOMA\(^2\) have confirmed the negative social image of Alzheimer’s disease, which is the third most feared disease by the general public. Social representations of the disease are particularly marked by the absence of the patient or by a more acute reminder of the advanced stages of the disease. The devastating impact of the disease on the patient’s family and friends is unanimously recognised by the general public, healthcare professionals and family carers. However, data from a pilot survey carried out among patients and family carers, which have been confirmed in the international literature, revealed that the way those affected perceive the disease subjectively is more subtle, providing scope for strategies to help patients in the early or moderate stages to adapt to the disease. It also seems difficult to identify the needs and expectations of the families in terms of support at home, apart from the fact that the services being proposed seem inadequate (in terms of flexibility, operating hours and duration).

In addition to these surveys, we wanted to investigate the perception of the professionals who provide assistance at home to persons with Alzheimer's disease. Data about their perceptions and actual practices is incomplete, while several measures included in the Alzheimer’s Plan (measure 1 on the experimental use of respite centres, measure 4 on Alzheimer’s patient integration and reception centres, measure 6 on pilot teams specialising in home nursing care services) are aimed at facilitating the patient’s care pathway and improving the level of support offered at home.

By quantifiably collecting the opinions of professional caregivers (nurses, nursing auxiliaries and other paramedical professionals) and assistance providers (area supervisors and social care workers) working in units participating in the trials, as well as those of professionals not affiliated to these units, the AidProf survey will help evaluate the impact of these trial home care schemes on the perceptions and practices of the relevant professionals.

**II. Objectives**

The survey’s general objectives will be to:

- establish an **initial baseline** for certain Alzheimer’s Plan monitoring indicators (only indicators regarding perceptions and practices of professional caregivers within the framework of the measures in which they are involved)\(^3\);

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\(^3\) Various agencies and organisations are involved in monitoring the plan’s epidemiological, organisational, health economic and structural aspects (InVS, CNSA and DREES, among others. For a complete list of indicators and the agencies responsible for monitoring them, visit the website http://www.plan-alzheimer.gouv.fr/)
The survey should make it possible to investigate:

- representations – images, attitudes and knowledge – regarding Alzheimer’s disease among professional caregivers (nurses, nursing auxiliaries, home helps and other professionals providing services within the framework of the home nursing care services (SSIAD), multifunctional home care and support services (SPASAD) or social and community-health cooperative associations (GCSMS)): their perceptions of the specialist teams and of the experimental scheme being proposed will be examined in particular;

- their professional practices (in terms of technique, relations and methodology) within the framework of caring for persons with Alzheimer's disease and their families and friends;

- their expectations and needs, in particular with respect to support, training and information.

By way of providing further explanation, the survey will try to answer a number of questions relating to the relationship between the social representations, professional practices and impact of new working arrangements on the practices and perceptions of professionals in particular. Our initial questions, which form the basis of this summary, relate to the differences in practices and perceptions both between professional caregivers and assistance providers and between participating and non-participating units. Other avenues will be explored later.

III. Methods

The quantitative survey was organised by Ipsos Santé and conducted by telephone from 17 November to 17 December 2009 in mainland France.

The survey was conducted among professionals affiliated to home nursing care (SSIAD) organisations, multifunctional care and assistance (SPASAD) units, as well as home care, assistance or support (SAD) agencies or organisations. It does not include private practice professionals whose work is not officially affiliated with a care or assistance unit, or professionals employed by mutual agreement (directly by patients or their families).

The survey does include organisations trialling respite centres, Alzheimer’s patient integration and reception centres, and specialist home nursing care (SSIAD) teams, and teams which did not apply to take part in the trials.

The sample was compiled in two stages:
- based on a file compiled using data extracted from the French National Social and Healthcare Institute Database (FINESS) and a list of participating organisations (7,349 addresses), 354 organisation representatives were identified, recruited and interviewed by means of a telephone questionnaire lasting approximately 35 minutes. Quotas based on the type of service provided (assistance or care), the legal status of the organisation and its reception capacity were set and served as a guide for creating the sample of organisations.

- using the file of contacts provided by the organisation representatives, 859 care and assistance professionals (79%) or roughly two professionals per unit were interviewed by means of telephone questionnaires lasting approximately 25 minutes.

In total, 1 213 professionals were interviewed in this survey. For analysis purposes and to simplify the interpretation of some of the findings, these professionals were grouped into broad categories according to the occupation they indicated at the beginning of the interview (Table 1).

### Table 1 – Number of people interviewed by professional category

<table>
<thead>
<tr>
<th>Profession indicated by person</th>
<th>Managers N = 426</th>
<th>Care professionals N = 486</th>
<th>Assistance professionals N = 301</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing coordinator</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Organisation manager</td>
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<td></td>
<td></td>
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<tr>
<td>Other officer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse</td>
<td></td>
<td>146</td>
<td></td>
</tr>
<tr>
<td>Nursing auxiliary</td>
<td>202</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other paramedical professional</td>
<td>292</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Area supervisor</td>
<td>101</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social care worker</td>
<td></td>
<td>197</td>
<td></td>
</tr>
<tr>
<td>Other assistant</td>
<td></td>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>

### IV. Results

1. **Profile of the units and professionals surveyed**

1.1 *Main features of the units and professionals surveyed*
Of the units surveyed, 58% were care units and 42% assistance units. There is a higher number of care units among the participating units surveyed (n=56).

Women make up the majority of the professionals surveyed (92% of care professionals and 97% of assistance professionals).

55% of those surveyed have been working in their unit for more than 6 years.

22% of care professionals are self-employed and attached to the unit.

On average, 26% of the service recipients suffer from memory problems resulting in a loss of independence and 16% suffer from Alzheimer’s disease.

These percentages are significantly higher in the care units than in the assistance units.

1.2 Differences between care units and assistance units

Care units are generally smaller organisations than assistance units (averaging 37 employees compared to 54), but offer more specialised care. In actual fact and logically, care professionals specify a higher level of training than assistance professionals and have more contact with patients suffering from memory problems or diagnosed with Alzheimer’s disease. Almost a quarter of care unit managers state that more than 41% of their patients have memory problems, whereas 68% of assistance unit managers reckon that less than 20% of their patients are affected by memory problems.

Similarly, there are more care unit managers who mention working in a team or having professional exchanges compared with assistance professionals, who seem to work in a more isolated way. For instance, 45% of care unit managers report having held team meetings (in contrast to 23% of assistance unit managers).

While roughly as many care units as assistance units belong to a federation (58% vs. 66%), 39% of care units are members of a healthcare network compared with only 25% of assistance units.

1.3 Differences between units participating and not participating in the trials

Fifty-six out of the 354 units (16%) are trialling Measures 1, 4 or 6, and 38 of those are care units. In total, 163 “participating” professionals (13%) were interviewed on the whole questionnaire.

The differences between the organisations participating in these experimental schemes and those not trialling them are evident, first of all, from the size of the units. The participating units employ and recruit more full-time staff than the non-participating units (42 vs. 14). The second difference concerns training. In fact, 52% of the participating units suggested training on Alzheimer’s or related diseases among their priority training areas, as opposed to only 33% of the non-participating units.

There is also a gap in terms of communication within the teams. The professionals in the participating units have easier access to opportunities for exchanging views, such as support groups (74%), professional practice analysis sessions (53%) and individual or group psychological support sessions (53%).

Finally, although there is no difference noted in terms of the proportion of persons affected by this disease who receive care from the units, the professionals interviewed from the participating units state that they work with a larger number of patients than professionals in the non-participating units (average of 34 per month compared to 22). Lastly, 55% of professionals affiliated with non-participating units, compared with 42% of professionals in participating units, agree that people with Alzheimer’s disease ought to be cared for in specialist facilities. Professionals in the participating units support keeping people suffering from this disease at home instead.
2. Perceptions of Alzheimer's disease and Alzheimer's patients

When asked about which three words or images come to mind when they hear the phrase “Alzheimer's disease”, the home care professionals mentioned terms which relate mainly to the following three categories:
- **dependence**, disability (73%)
- **loss of mental faculties**, madness (50%)
- **memory loss** (43%).

These three categories are identical to those highlighted in the survey carried out among the general population, although the order is different as the general public mentioned memory loss (69%) first, ahead of dependence (53%) and loss of mental faculties (34%). It should also be noted that there is a difference between the care and assistance professionals with regard to the importance attached to these three aspects, with carers tending to be more in tune with the statements of the general public.

Even more markedly than in the case of the general public, **gloomy images or aspects of the disease are seldom referred to.**

On the other hand, a **wider variety of images** associated with Alzheimer’s disease is noted among the professionals: words or ideas associated with resources and facilities and with the need for recognition of the patients or terms such as “love” and “dignity” feature in their spontaneous perceptions, whereas they were not mentioned by the general public.

Alzheimer’s disease is perceived by almost all the professionals surveyed, and in a more pronounced way than among the general population, as a disease which can have a **devastating impact on patients’ families** (99% compared to 93% of the general public), as a **disease affecting a growing number of people** (87% vs. 83%) and as one that **can also affect people in their 40s** (93% vs. 80%).

The view is less unanimous regarding other opinions presented to the respondents: 59% of the professionals surveyed say that it is normal to suffer memory loss with old age (compared to 74% of the general public); 68% consider that television, newspapers and magazines should talk more about Alzheimer’s disease (compared with 79%); and 53% think that Alzheimer’s patients should be cared for in specialist facilities.

3. Support practices

In our survey 45% of the people questioned know someone in their circle of friends and family who has Alzheimer’s disease (38% among the general public), most often a family member.

Professional proximity to the disease is more common. With the exception of unit managers and representatives, professionals (n=916) were questioned regarding the number of affected patients with whom they work every month: 12% of these professionals said they do not work with Alzheimer’s patients. This figure is significantly higher among assistance professionals (25%) than care professionals (7%). On average, **caregivers report working with 25 patients per month**, accounting for one quarter of the patients cared for by these professionals, while **assistants report working with 7 patients a month**, or one fifth of the recipients of assistance.

We have no indication of the level of dependence of the persons cared for by the professionals surveyed. On the other hand, we were able to evaluate the kinds of difficulties or specific issues relating to these care recipients which the professionals involved encountered most
often. 57% of the professionals caring for at least one Alzheimer’s patient per month (n=802) report that all or most of the patients they monitor experience difficulty understanding, 45% show signs of depression, 23% have difficulty speaking, 17% display aggressive behaviour and 12% try to run away. A third of professionals also mention signs of recognition from most or all of the patients being looked after.

Support for persons with Alzheimer’s disease is most often provided in the presence of a third party, a family member or less often a healthcare professional or other colleague. With regard more specifically to the kind of assistance provided, the survey allows us to evaluate the different attitudes of the care and assistance professionals, in particular with respect to specific actions which raise issues in terms of delegation and responsibility. For example, 85% of nursing auxiliaries surveyed, 61% of nursing coordinators, 45% of social assistants and 35% of nurses employed by or attached to the unit state that they regularly help Alzheimer’s patients to wash and dress; 40% of nursing auxiliaries and 39% of social care workers state that they regularly help patients to get around; and 48% of nurses, 30% of social care workers and 21% of nursing auxiliaries state that they regularly manage patients’ drugs. The role of other paramedical professionals appears to be becoming less prominent, with more infrequent contact, primarily focusing on counselling for friends and family and assessments of patients’ independence and abilities.

The professionals surveyed were not always familiar with the support or care plan for the Alzheimer’s patients in their care: 17% of assistance professionals and 8% of carers among those who work with at least one patient affected by this disease state that they are never familiar with the plan. As a result of this limited familiarity with the support or care plan, only a third of the professionals surveyed say that they are always involved in producing the plan, this figure being significantly lower among assistance professionals (16%).

Even if they are not always familiar with the support or care plan, 67% of professionals working with Alzheimer’s patients agree that they have adequate information on patients’ histories, tastes and preferences, and 75% consider that they exchange enough information on patients with other care providers. However, the latter opinion is not as prevalent among assistance professionals (70% vs. 76% of care professionals) (Figure 1).

Figure 1 – Percentage of professionals indicating that they “absolutely” or “probably” agree with specific statements regarding their role
4. Feelings of competence and perceived difficulties

While eight out of ten professionals surveyed among all the respondents (n=1,213) consider themselves very well informed or well informed about Alzheimer’s disease in general (compared with 62% among the general population and 75% of family carers), only 39% state that they understand the causes of Alzheimer’s disease very well or well. In general, the feeling of being informed is significantly higher among professionals working in the units experimenting with the new methods of care than among the other professionals (89% vs. 81%). There is also a higher number of care professionals who state that they are well informed than assistance professionals (85% vs. 74%). Holding a healthcare or social work qualification and having had ongoing training on Alzheimer's disease are in fact correlated with a more positive assessment of how well informed one is.

The main sources of information for professionals are professional journals (for 46% of all the professionals surveyed, with 52% for care professionals and 30% for assistance professionals), initial or continuing vocational training (39%), the media (31%) and the Internet (26%).

A large majority of respondents (92%) believe that there are treatments to improve the wellbeing of patients (whereas only eight out of ten of the general public thought the same thing).

Among professionals working with Alzheimer’s patients (n=802), nearly nine out of ten agree that they can definitely or probably improve Alzheimer’s patients’ quality of life (Figure 1). When questioned regarding their ability to manage certain specific aspects of
Alzheimer’s disease, three quarters of professionals consider that they manage relationships with close family and friends of Alzheimer’s patients very easily or easily. Perceived ability is lower with respect to communication with Alzheimer’s patients at advanced stages of the disease or when they refuse to be helped or cared for (42% of respondents believe that they succeed in managing these issues very easily or easily). The aspect which appears to be the most difficult to manage, for 69% of these professionals, is the isolation of Alzheimer’s patients. Care professionals and managers, and especially nursing coordinators and nurses, are significantly more likely to experience difficulties with this situation. Despite this, 67% of respondents believe that they receive adequate support in carrying out their work. This feeling varies considerably from occupation to occupation, with nurses and paramedical professionals scoring lower in this area than other professional categories.

5. Knowledge of the Alzheimer’s Plan and the measures concerning support at home

Almost nine out of ten professionals (86%) have heard of the Alzheimer’s Plan and half of the professionals surveyed are able to quote measures spontaneously, either exactly (Alzheimer’s patient integration and reception centres (MAIA), home nursing care services (SSIAD)/Measure 6, specialist residential care units for the elderly (EHPAD), creation of the post of gerontology care assistant, etc.) or less explicitly (development of research, keeping patients at home, development of facilities, etc.). As would logically be expected, the participating units have a greater knowledge of the Plan, even though 22% of the professionals affiliated with a participating unit have not heard of the Plan or cannot quote a measure from it.

As in the case of the general public, the professionals were asked which objectives should be the government’s top priorities in tackling Alzheimer’s disease. While the general public mentioned research as the priority objective, the professionals, regardless of the profession or type of unit, mostly give priority to providing relief for families and keeping patients at home.

V. Discussion and conclusion

Data on support for persons with Alzheimer’s disease provided by home care and home assistance professionals in France are patchy. The survey conducted by INPES enables us to fill in some of the gaps by providing a descriptive inventory of the perceptions of professionals regarding Alzheimer’s disease and Alzheimer’s patients, the work done with these groups, the difficulties encountered and the professionals’ expectations and needs. **This description is not exhaustive.** The study targets care and assistance units and excludes professionals in private practice (in particular, nurses) from the survey, although these professionals are key actors in the provision of home care for Alzheimer’s patients. It also excludes assistants (home helps, social care workers) employed directly by patients or their families who are not affiliated with home assistance units. It is assumed that these professionals have a specific profile in terms of initial and continuing vocational training, career and working conditions.

4 According to an MSA survey (2000) involving 702 patients with Alzheimer’s disease, 23% of patients had occasionally received technical nursing care and 17% had received more regular hygiene care, monitoring, prevention and observation, all provided by private nurses, while only 10% had received care from a home nursing care service (SSIAD).
The study’s other limitation concerns the assessment of the dependence of the persons being looked after by the care and assistance units. This is difficult to understand but could have provided some clues to account for the differences noted between care and assistance units or among different professionals. Therefore, one can only assume that the situations encountered by these different professionals and their impact on support vary according to the stage of the disease and associated difficulties.

Finally, the low level of involvement of the participating units makes it difficult to ensure that these organisations are well represented, especially those involved in Measure 6 of the Alzheimer’s Plan.

In spite of these limitations, some salient points can be drawn from the study.

First of all, the results for the professional care assistants provide a more in-depth social perspective of Alzheimer's disease by confirming the images spontaneously associated with this condition, which revolve around dependence, memory loss and loss of mental faculties. These three images, mentioned as much by the general public as family carers or assistance or care professionals, tend to confirm the dual tendency to present the disease as a medical and social issue, as described in the international literature, and only slightly mitigate the conflict between Alzheimer’s disease and old age or ageing (Scodellaro and Pin, 2008). As indicated in the qualitative study carried out among the general public, the actual patient and his or her feelings and experience feature little in the minds of the professionals surveyed. The constant image is that of the care situation, loss of independence and the burden on family and friends. These findings call for an assessment of the patient at early and moderate stages of the disease, as well as the task of identifying the role of assistance and care professionals during the less advanced stages of the disease, to be carried out in conjunction with these professionals themselves. A new rehabilitation service (Measure 6) is being tried out with this in mind.

Contrary to the emphasis placed on support and the medical and social consequences of the disease, the associations are less gloomy and negative than expected. The professionals surveyed appear therefore to be generally satisfied with their working conditions and optimistic about their ability to make a positive impact on their patients’ lives and, on the whole, have few difficulties related to the disease’s specific nature. As a result of previous national programmes and the current plan, Alzheimer’s disease is seen as a priority area for training within the units and as one of the areas most valued by the professionals surveyed during their continuing vocational training. Admittedly, as we expected, significant differences exist between the different professional categories, but these cannot be reduced to a dichotomy between assistance professionals and care professionals. On the issues of initial and continuing training and the level of knowledge and information, social care workers lag behind. They are more likely to be isolated when doing their job and do not enjoy the time and tools for facilitating exchanges of views as often as their colleagues do. Nevertheless, they exhibit fewer difficulties than nursing auxiliaries, and even fewer than nurses with respect to certain specific features of Alzheimer’s patients, such as communication with patients at advanced stages of the disease, refusal of care or isolation. Social care workers are also significantly more likely to notice signs that patients recognise them. This particular aspect of home assistance work has been described in several qualitative studies carried out in France. It goes beyond the difficulties encountered and the increased responsibility taken on to support persons suffering from cognitive problems, and highlights the reported pleasure in working with these groups which require “improvisation, adaptation
to the unexpected and acceptance of the temporary nature of things”\(^5\). These elements need to be integrated into support and training programmes designed for care and assistance professionals, both to identify points for improvement and to highlight and share those aspects experienced as positive by home assistants and the strategies these actors have developed to adapt to the specific aspects of Alzheimer’s disease. In our view, and for those professionals working in care and assistance units, these programmes must be designed more to reinforce skills and acknowledge the work done than to respond to any specific need.

The survey had another, more ambitious aim, which was to explore certain relations between practices and perceptions and to identify the factors associated with these aspects. Additional analyses are required to understand these relations, which will also be investigated in greater depth as part of a qualitative study. **An overall report will be available in September 2010.** It will feature the results of a module aimed at GPs, the trends and supplementary analyses deriving from the survey carried out among assistance professionals, as well as the results of an additional qualitative survey for which the field work will be carried out in May and June.

\(^5\) Guichet and Hennion (2009), p.126