

# Timely Diagnosis of Dementia

## ALCOVE WP5 Task 1 and 2

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# Rationale

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The provision of care and support for people living with dementia and their families has in recent years become a worldwide cause for concern (Prince & Jackson, 2009). A number of factors have given rise to this concern including the increasing numbers of people living into older ages who are at greater risk of developing dementia, and furthermore, the health and social care costs associated with this increase (Prince & Jackson, 2009, Prince *et al.* 2011b). Prince and Jackson identified that a 40% rise in the numbers of people living with dementia can be expected in Europe over the next 20 years.

Research has highlighted that many people do not ever receive a diagnosis of dementia and that furthermore, where a diagnosis does occur, it is frequently much later in the experience of dementia, when clinical signs have progressed and activities of daily living, cognition, relationships, behaviour and quality of life are already significantly challenged (Bamford, *et al.*, 2004, Carpenter & Dave, 2004, Prince *et al.* 2011b).

In response to this, a number of countries have set targets within their dementia strategies for early diagnosis, for example the Department of Health in England identified that a core aim is *“to ensure that effective services for early diagnosis and intervention are available for all on a nationwide basis”* (Department of Health, 2009: 33). However it is necessary to define clearly what is meant by early as opposed to later diagnosis given such issues as the current debate concerning diagnosis and interventions in the prodromal (pre-clinical) phase of Alzheimer’s disease.

Prince *et al.* (2011b: 12) define a four stage timeline of disease progression:

1. Time point one (T1), neuropathology but no clinical signs, is the earliest possible point of diagnosis if reliable biomarkers are developed;
2. Time point two (T2), neuropathology, early cognitive changes and possible disability, subjective impairment and help seeking, earliest possible diagnosis using currently available technology;
3. Time point 3 (T3), onset of cognitive decline and disability, subjective impairment and/or help seeking, focus on timely diagnosis, responding to patient and carer concerns rather than proactively screening for the disease;
4. Time point 4 (T4), significant evidence of cognitive decline and disability, help seeking, current late stage diagnosis.

A report published by Alzheimer's Disease International in 2011 (ADI, 2011) suggests that up to 28 million of 36 million people living with dementia across the world have yet to receive a diagnosis, limiting their access to treatment, information and care. The report also states that lack of detection is a significant barrier to improving the lives of people with dementia, as well as their families and their carers, and that the costs of early detection can be offset by projected future savings. The report recommends that every country should have a national dementia strategy that promotes early diagnosis and intervention.

The European Union (EU) has been quick to respond to this increasingly urgent agenda and to recognise the need to address the health, social and economic issues that dementia poses for society. In 2007 the European Commission (the EU's executive body) funded the project "European Collaboration on Dementia – EuroCoDe". This project, led by Alzheimer Europe, included work to provide an overview of International, European and National guidelines on the diagnosis and treatment of dementia (Alzheimer Europe, 2010).

In 2009, the European Parliament adopted a Written Declaration (Grossetete et al., 2008) on the priorities in the fight against Alzheimer's disease. This declaration called on the European Commission and the Member States to develop a European Action Plan and to collaborate in order to improve early diagnosis and the quality of life of people with dementia and their carers. In July 2009 the European Commission issued a commitment to support member states in addressing the issue of dementia.

Within this context, the European Commission instigated a European initiative on Alzheimer's disease and other dementias ALCOVE: The European Joint Action on dementia to exchange good practice. This initiative required the European Commission to use its different programmes (including Health and Disability) in an integrated way, with the Commission supporting member states in addressing the issue of dementia.

The EU Joint Action on Alzheimer's initiative (ALCOVE) was launched in 2011 in an effort to step up cooperation and support to improve dementia prevention, diagnosis, treatment and care across EU Member States. ALCOVE is a 2-year project and four core areas are to be addressed:

1. How to improve data for better knowledge about dementia prevalence;
2. How to improve access to dementia diagnosis as early as possible;
3. How to improve care for people living with dementia and particularly those with behavioural disorders;

4. How to improve the rights of people with dementia, particularly with respect to advance declarations of will.

ALCOVE consisted of seven Work Packages, each led by a different EU country:

- Work Package 1 – France
- Work Package 2 – Spain
- Work Package 3 – Slovakia
- Work Package 4 – Italy
- Work Package 5 – United Kingdom (UK)
- Work Package 6 – Finland
- Work Package 7 - Belgium

The Association for Dementia Studies (ADS) was commissioned by the UK Department of Health to lead on Work Package 5, which aimed to compare national recommendations for the diagnosis of dementia in order to access a common definition with associated operational criteria, and to evaluate diagnostic systems in EU member states in order to formulate recommendations for improving early diagnosis.

This report is a record of this undertaking.

# Method – Review of Literature

Initial literature searches were carried out by partners in Slovakia, France and Sweden, alongside a synthesis of diagnostic criteria utilised in Spain and Greece. The results of the literature searches are reproduced in Tables 1, 2 and 3 below. These searches were informed by the goals of the review.

*Table 1: Search by Sweden*

| Partner        | Search Terms  | Limits         | Database       | Results |
|----------------|---|----------------|----------------|---------|
| Mesh Headings: |   |                |                |         |
| Sweden         | Dementia OR Alzheimer's Disease AND Diagnosis AND Review Literature As Topic      | Not identified | Medline        | 20      |
| Mesh Headings: |   |                |                |         |
| Sweden         | Dementia OR Alzheimer's Disease AND Mass Screening                                | Not identified | Medline        | 756     |
| Mesh Headings: |   |                |                |         |
| Sweden         | Dementia OR Alzheimer's Disease AND Mass Screening AND Meta-analysis as topic     | Not identified | Medline        | 2       |
| Mesh Headings: |   |                |                |         |
| Sweden         | Dementia OR Alzheimer's Disease AND Mass Screening AND Review Literature as Topic | Not identified | Medline        | 1       |
| Mesh Headings: |   |                |                |         |
| Sweden         | Dementia or Alzheimer's Disease AND Mass Screening AND Practice Guideline         | Not identified | Medline        | 6       |
| Sweden         | Mesh Headings: Dementia OR Alzheimer's Disease AND Screening AND Guideline        | Not identified | PUBMED<br>PMID | 462     |

Table 2: Search by France

| Partner | Search Terms   | Limits  | Database | Results |
|---------|--|---|----------|---------|
| France  | <p>[(dementia OR alzheimer Or memory OR Mild cognitive impairment) title OR "Alzheimer Disease"[Majr] OR "Dementia"[Majr:NoExp] OR "Memory Disorders"[Majr] OR "Cognition Disorders"[Majr] AND ("Mass Screening"[Mesh] OR "Early Diagnosis"[Mesh]) OR (detection Or screen* or diagnos*)title</p> <p>OR</p> <p>("Memory Disorders/diagnosis"[ Majr:NoExp] OR "Alzheimer Disease/diagnosis"[ Majr:NoExp] OR "Dementia/diagnosis"[ Majr:NoExp] OR "Cognition Disorders/diagnosis"[Majr:NoExp]))</p> <p>AND</p> <p>"Health Services for the Aged"[Mesh:NoExp] Or "Organization and Administration"[Mesh:NoExp] OR "Health Services"[Mesh:NoExp] OR "Primary Health Care"[Mesh:NoExp] OR "Physicians, Primary Care"[Mesh:NoExp] OR "Community Health Services"[Mesh:NoExp] OR "Preventive Health Services"[Mesh:NoExp] OR (Primary care Led clinic* OR "secondary care" OR "tertiary care" OR acute)title</p> <p>OR</p> <p>(memory service OR memory clinics OR neurology* diagnos*)</p> | <p>European Languages</p> <p>Date Limit<br/>2005<br/><br/>to<br/>2011</p>     | Medline  | 465     |
| France  | <p>"Memory Disorders/diagnosis"[ Majr:NoExp] OR "Alzheimer Disease/diagnosis"[ Majr:NoExp] OR "Dementia/diagnosis"[ Majr:NoExp] OR "Cognition Disorders/diagnosis"[Majr:NoExp]</p> <p>AND</p> <p>[(dementia OR alzheimer Or memory OR Mild cognitive impairment) title OR "Alzheimer Disease"[Majr] OR "Dementia"[Majr:NoExp] OR "Memory Disorders"[Majr] OR "Cognition Disorders"[Majr] AND ("Mass Screening"[Mesh] OR "Early Diagnosis"[Mesh]) OR (detection Or screen* or diagnos*)titleOR (memory service OR memory clinics OR neurology* diagnos*)</p> <p>AND "Costs and Cost Analysis"[Mesh] OR "Economics"[Majr] OR "Cost-Benefit Analysis"[Mesh]</p>   | <p>All European Languages</p> <p>Date Limit<br/>2000<br/><br/>to<br/>2011</p> | Medline  | 116     |

*Table 3: Search by Slovakia*

| <b>Partner</b>                 | <b>Search Terms</b>              | <b>Limits</b>  | <b>Database</b> | <b>Results</b> |
|--------------------------------|----------------------------------|----------------|-----------------|----------------|
| <b>Slovakia</b>                | 1) Dementia Diagnosis criteria   | Not identified | PUBMED          | 6350           |
| <b>Slovakia</b>                | 2) Dementia Diagnosis criteria   | Not identified | PUBMED          | 6484           |
| <b>Slovakia</b>                | 3) Dementia Diagnosis Definition | Not identified | PUBMED          | 516            |
| <b>Slovakia</b>                | 4) = Search 1) or 3)             | Not identified | PUBMED          | 6690           |
| <b>Slovakia</b>                | 5) =Search 4) or 2)              | Not identified | PUBMED          | 7037           |
| <b>Slovakia</b>                | 6) Search 5) AND Questionnaire   | Not identified | PUBMED          | 458            |
| <b>Articles Retrieved= 122</b> |                                  |                |                 |                |

Following receipt of 1855 abstracts a review of title and abstract content and date was undertaken to select those articles relevant to the goals.

Members of the Association for Dementia Studies (ADS) responsible for this work package then met following the ALCOVE Executive Board & Steering Committee in Paris, April 2012 to formulate a structure for the literature review, which was informed by discussions at the meeting in Paris. The structure of the literature review was circulated to members of the steering group and subsequently considered at the meeting of the steering and reference groups for Work Package 5, held in July 2012. The structure is outlined in Table 4 below.

Table 4: Agreed Structure of Literature Review

|  | MCI   | Early Diagnosis  | Moderate to Late Diagnosis  |
|--|---|--|---|
| <b>Differential diagnosis</b><br>a. To rule out other conditions<br>b. address specific groups <ol style="list-style-type: none"> <li>I. early onset dementia</li> <li>II. people with learning disabilities</li> <li>III. older people</li> <li>IV. people from black and minority ethnic communities</li> </ol> c. To address complex differential diagnosis e.g. <ol style="list-style-type: none"> <li>I. Alcohol misuse</li> <li>II. Rarer forms of dementia</li> <li>III. Neuropsychiatry (e.g. Huntington's etc)</li> <li>IV. co-morbidity</li> </ol> |   |  |   |
| <b>Diagnostic Classifications</b>  | Amnesic MCI or non-amnesic MCI (but not a diagnosis currently, a label) | 4 main types: <ol style="list-style-type: none"> <li>1. Alzheimer's disease</li> <li>2. Vascular Dementia</li> <li>3. Dementia with Lewy Bodies</li> <li>4. Frontotemporal dementia and subtypes</li> <li>5. Rarer forms linked to differential diagnosis</li> </ol> Identify the potential for identification of different types, | Possible but increasingly likely to be general classification of dementia |
| <b>Criteria for diagnosis in each of the diagnostic subtypes</b>   | Currently label rather than diagnosis                                   | Yes  | Possible  |
| <b>Who presents at each stage and what are they presenting with, what are the issues influencing this e.g.</b> <ul style="list-style-type: none"> <li>• Awareness</li> <li>• Stigma</li> <li>• Willingness to test</li> <li>• Service provision</li> <li>• Treatment availability</li> <li>• Ethical issues</li> <li>• Consent</li> <li>• Legal requirements</li> </ul>  |   |  |   |
| <b>Who do they present to?</b>   |   |  |   |
| <b>How long before presenting (Factors influencing this)</b>   |   |  |   |

|   |  |  |  |
|---|--|--|--|
| <b>What process should be delivered and by who</b>  |  |  |  |
| <ol style="list-style-type: none"> <li>1. Primary Care/ Community Staff</li> <li>2. Specialist Mental Health Services</li> <li>3. Neurology</li> <li>4. Acute Care</li> <li>5. Nursing/ Residential Care</li> </ol> |  |  |  |
| <b>What are the key challenges facing the practitioner/ person/ family at this stage?</b>   |  |  |  |
| <b>What are the benefits/ drawbacks</b>   |  |  |  |
| <b>Reported current practice from completed questionnaires</b>  |  |  |  |
| <b>Recommendations at each stage, which should inform government departments on next steps</b>  |  |  |  |
| <b>What happens next, processes and challenges</b>  |  |  |  |
| <b>What does this mean? next steps and workforce issues</b>   |  |  |  |

This structure proposed 3 sections to the literature review, Mild Cognitive Impairment, Early Diagnosis and Moderate to Later Diagnosis. Following further discussion with HAS, it was agreed that a brief section considering population screening should also be provided. During July 2012, further literature searches were carried out to address the areas of the review not covered in the searches already undertaken. These are outlined in Table 5. Furthermore, the original searches were rerun to identify any further articles published since they were undertaken. Additionally, references lists in articles and documents that were selected were hand searched, as were journals such as Dementia, Aging and Mental Health and The Journal of Nutrition Health and Aging, where appropriate to identify further relevant references. Finally, colleagues with expertise in these areas were consulted concerning appropriate references.



Table 5: Further Literature Searches

| Search Terms  | Limits   | Database  | Results |
|---|--|---|---------|
| <b>Dementia OR Alzheimer's Disease AND Downs Syndrome OR Intellectual Disability OR Learning Disability AND Diagnosis</b> | English Language<br>Date 2000 to 2011<br>Peer review journals                | Medline<br>Psychinfo<br>Psycharticles                                       | 207     |
| <b>Dementia OR Alzheimer's Disease AND Diagnosis AND Careg*(Major Headings)</b>   | English Language<br>Academic Journals<br>With Abstracts<br>Date 2009 to 2012 | Academic Search Complete<br>Psychinfo<br>Psycharticles<br>Cinahl            | 460     |
| <b>Dementia AND Acute Care</b>  | No Limits  | Academic Search Complete<br>Psychinfo<br>Psycharticles<br>Cinahl<br>Medline | 123     |
| <b>Dementia AND Diagnosis AND Care Homes OR Nursing Homes (Major Headings)</b>  | 2009-2012  | Psychinfo<br>Cinahl   | 1035    |
| <b>Dementia AND Diagnosis AND Ethnicity OR Minority Ethnic Communities OR Migrant Communities</b>                         | 2000-2012  | Psychinfo<br>Psycharticles<br>Cinahl<br>Academic Search Complete            | 62      |
| <b>Dementia AND Early Diagnosis AND Quality of Life</b>   | No limits  | Psychinfo<br>Psycharticles<br>Cinahl<br>Academic Search Complete            | 67      |

A total of 237 references were selected to inform the production of the literature reviews. The types of references utilised in these reviews are outlined in Table 6.

*Table 6: References used in the review*

| Type of reference           | Number | Type of reference   | Number |
|-----------------------------|--------|---|--------|
| Quantitative Research (QuR) | 89     | Qualitative Research (QR)   | 22     |
| Mixed Methods (MM)          | 10     | Systematic Review / Meta-Analysis(SR)   | 18     |
| Review (R)                  | 56     | Criteria/ Guidelines (CG) formed from Quantitative Research and/ or Expert Analysis of existing cases | 22     |
| Practice Commentary (PC)    | 9      | Reports (Rep)   | 8      |
| Book Chapter (B)            | 3      |   |        |

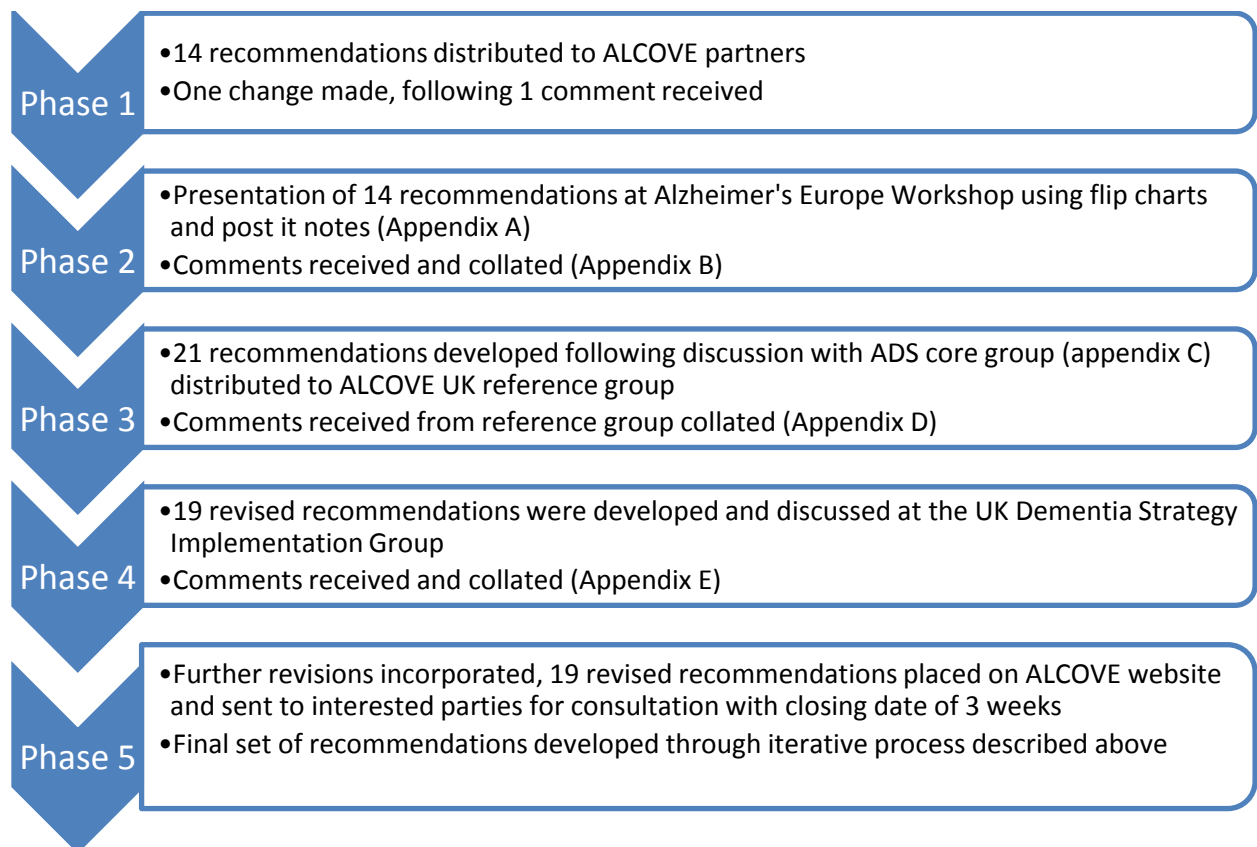
In the reference lists at the end of each literature review, the type of reference is identified along with the country in which the research was undertaken. References were read to obtain the core results and to identify their relevance to the different sections in each of the 4 literature reviews. Each reference was then reread, and the significant outcomes were collated for each topic under consideration. Where available, results of systematic reviews were incorporated due to the additional methodological rigour employed to arrive at their conclusions. Each section of the literature review was then written, synthesising results from a range of sources as appropriate to the issue being discussed. The 4 reviews were then sent out to the reference group for comments and feedback. Ten sets of comments were received, two for the section on population screening, five for the section on mild cognitive impairment, one for the section on early diagnosis and one for the section on moderate to later diagnosis. The comments received were broadly supportive. Where comments received were contrary or contradictory to the review, they were weighed up with the evidence and discussed by the core ADS team, who then made decisions about whether changes should be made.

This review has a number of limitations. Firstly, the references reviewed were restricted to English Language only, thus references available in other languages have not been included. Secondly, references reviewed were primarily limited to publications within the last 5 years, as there have been considerable advancements in the field of early diagnosis and intervention in recent years. However, where appropriate, references of a seminal or significant nature were sought and used in the review. Thirdly the articles reviewed predominantly reflect research, policy and practice derived from countries with well developed systems of health and social care, including Northern and Central Europe, USA and Canada.

## Developing the recommendations from the literature reviews

Following completion of the reviews, a list of 14 recommendations were identified and distributed to ALCOVE partners immediately prior to the Alzheimer Europe conference. Figure 1 identifies the process undertaken to refine these recommendations. As with the literature reviews, it should be noted that changes made to these recommendations involved an iterative process in which those changes that were contrary to the recommendations were weighed up alongside the evidence and discussed by the core ADS team, with changes being made where these were considered appropriate and congruent with the evidence base.

Figure 1: Recommendation development process



# Method – The Early Diagnosis Questionnaire

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## Phase 1 – June 2011-December 2011

### Initial questionnaire design

The questionnaire was originally produced as a Microsoft Word document and was divided into six main sections:

1. Country data – Seven questions gathering data about the number of professionals in different roles;
2. Diagnosis – Six questions regarding who makes a diagnosis and details of any screening services available;
3. Theory vs. Practice – Seven questions comparing official recommendations against what is actually carried out in day-to-day practice;
4. Legal framework – Eight questions regarding what legislation is in place regarding people with dementia, in particular the use of advance directives;
5. Health organisations – 13 questions about the accessibility of different health services;
6. Relationships between General Practitioners (GPs) and specialists – Ten questions investigating the information exchange that takes place between the two groups of professionals.

### Response collection

The 27 EU Member States were grouped into five broad geographical areas as shown in Table 7. A coordinating country was appointed for each region, and these are highlighted in Table 7.

*Table 7: Grouping of the 27 EU Member States*

| Central        | Eastern   | Northern    | Southern | Western        |
|----------------|-----------|-------------|----------|----------------|
| Austria        | Estonia   | Denmark     | Cyprus   | Belgium        |
| Bulgaria       | Latvia    | Finland     | Greece   | France         |
| Czech Republic | Lithuania | Germany     | Italy    | Ireland        |
| Hungary        | Poland    | Netherlands | Malta    | Luxembourg     |
| Slovakia       | Romania   | Sweden      | Portugal | United Kingdom |
| Slovenia       | -         | -           | Spain    | -              |

The coordinators were given the task of disseminating the questionnaire electronically or as a paper copy to appropriate personnel in each country within their region. The coordinators were also responsible for following up delayed or missing responses. The deadline for questionnaire responses was initially set as the end of October 2011, which was prior to ADS joining the ALCOVE project.

## **Phase 2 – January 2012-September 2012**

### **Questionnaire redesign**

By January 2012 only five completed questionnaires had been received, so it was decided that ADS would create a newer version of the questionnaire which would hopefully be easier for each country to complete. The main changes made to the questionnaire were:

- Rewording some of the questions to make them clearer;
- Redesigning the layout of some parts of the questionnaire to make it clearer and easier to fill in;
- Using the responses received to restructure some questions by providing options to select as a means of standardising responses;
- Adding a question regarding psycho-social interventions;
- Putting the questionnaire online to give countries the option to complete it via the Internet.

### **Response collection**

The new Word version of the questionnaire and a link to the online version were sent to each coordinator for dissemination to the countries within their region, regardless of whether or not they had previously responded. Any countries that completed the original version of the questionnaire were sent the new question regarding psycho-social interventions in an attempt to gain this additional information.

Following the questionnaire redesign, contact was made between the ADS team and the coordinators on numerous occasions to prompt them to send reminders to countries that had not responded. The ADS team also contacted a number of people in individual countries directly to encourage completion of the questionnaire, and this was generally found to be an effective approach.

## Responses received

Table 8 details the timeline for questionnaires returned during the period June 2011 through to September 2012.

*Table 8: Timeline of questionnaire returned*

| Phase   | Time point     | Actions/Comments   | Number of questionnaire responses received |
|---------|----------------|--|--|
| Phase 1 | June 2011      | Original questionnaire designed and sent out via regional coordinators               | -  |
|         | October 2011   | Original questionnaire deadline  | -  |
|         | December 2011  | ADS joined ALCOVE project  | 5 in total                                 |
| Phase 2 | January 2012   | Questionnaire redesigned   | -  |
|         | February 2012  | ADS contacted countries directly. Regional coordinators prompted to remind countries | 15 in total                                |
|         | May 2012       |  | 20 in total                                |
|         | July 2012      |  | 23 in total                                |
|         | September 2012 |  | 24 in total                                |

## Analysis

The results from the questionnaire were considered separately for each of the six sections within the questionnaire. The analysis methods used for the questionnaire varied depending on the individual question. For some questions it made most sense to show the responses of the different countries whereas for others it made sense to show the responses grouped by response mode. The wide range of responses from countries that are often very different also meant that using the same method for each question was not possible, but four of the main approaches used are listed here. The analysis carried out was mainly descriptive rather than statistical.

### Standardising responses

The countries within the EU represent vary considerably in terms of both their geographical sizes and populations, so it was difficult to compare responses that are based on raw numbers. To make comparisons more meaningful responses involving population figures in different age ranges were converted into a percentage of the total country population, and the numbers of professionals in different roles were converted into the number per 1000 people aged 65+, as this is the target patient group we are

interested in. Similarly, the numbers of memory clinics and services were converted into the number of people aged 65+ per clinic or service to allow fairer comparisons to be made.

### **Ranking countries**

Although countries are not ranked in terms of being better or worse than others, the results for some questions are presented in an ordered fashion to show the range of responses. An EU median value is also provided for reference in these cases.

### **Grouping countries**

For questions where there was a set of standard responses to choose from, countries are grouped together if they responded in the same way. For example, countries that have National Official Guidelines for Diagnosis are grouped separately from those without such guidelines in place.

### **Frequency of responses**

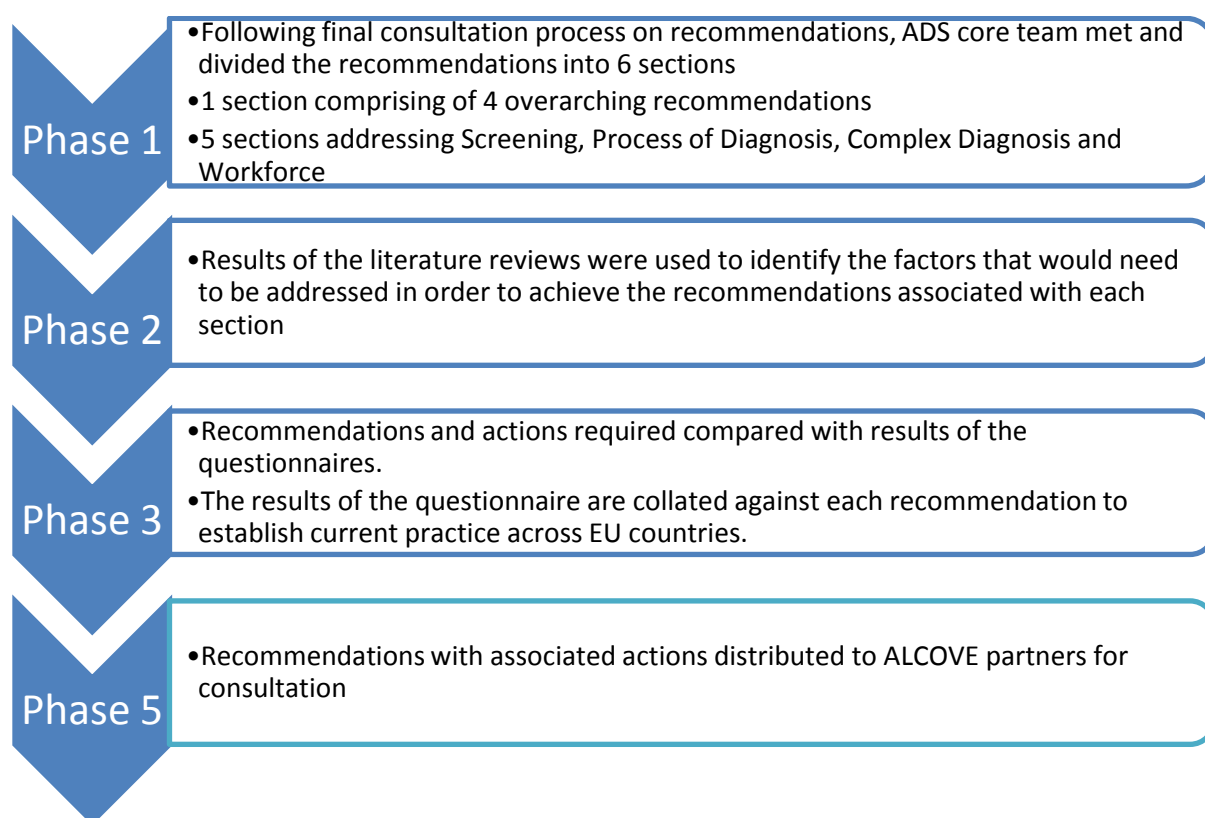
Some questions allow countries to select or provide multiple answers, and in these cases the results are generally presented as frequency charts to show which the most common responses were.

# Method – Development of Final Recommendations

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Figure 2 describes the process used to achieve the final recommendations for this work package, which provide recommendations with associated actions required to achieve them. These were developed using an iterative process of comparing the evidence base with the final recommendations and the results of the questionnaire.

*Figure 2: Iterative process of recommendation development*



The Results Section reflects this process and comprises of:

- The 4 literature review sections (Screening, Mild Cognitive Impairment, Early and Timely Diagnosis and Moderate to later Diagnosis);
- The collated results of the survey questionnaires;
- The recommendations with associated actions and current practice against these recommendations.



# Results – The Literature Review

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## Section 1: Diagnosis at Time Point 1, Population Screening

Early diagnosis and intervention are key priorities in many European dementia strategies and in many high income countries across the world Prince *et al.* (2011b). The economic, personal, health and social care costs of dementia have been emphasised and have prompted further research into causes, treatment and prevention (Prince *et al.* 2011b, Andrieu, *et al.*, 2011, Wimo and Prince, 2010, Comas-Herrera, *et al.* 2007, Welsh-Bohmer, 2008). Within this burgeoning area of research, the life course perspective for the risk of developing dementia has prompted research exploring enhanced methods of detecting and intervening early and specifically with Alzheimer's disease and vascular dementia, achieving this in the pre-clinical phase of the condition to prevent or delay onset (Andrieu, *et al.* 2011). In recent years research has advanced in early detection, and has developed biomarker tests which measure tau protein levels and amyloid-beta levels in cerebrospinal fluid (Brooks & Loewenstein, 2010; Budson & Solomon, 2012; Levey *et al.*, 2006) and changes in brain structure, magnetic resonance imaging, computerised tomography, and flurodeoxyglucose positron emission tomography (Budson & Solomon, 2012; Fennema-Notestine *et al.*, 2009; Maioli *et al.*, 2007; Rossi *et al.*, 2007; Visser *et al.*, 1999). Currently the use of biomarker tests has been restricted to research and is not recommended for clinical practice, not least because further research is required to establish their ability to predict progression to dementia (Prince, *et al.*, 2011b, Sperling, *et al.*, 2011, Eschweiler, *et al.*, 2010, Lopez, *et al.* 2011). Furthermore, the Dubois research criteria (2010) for Alzheimer's disease which recommends the use of biomarkers as part of the assessment has not been evaluated for use in clinical practice (Cedarbaum, Crans & Grundman, *et al.* 2010).

While rarely utilised in clinical practice, the advent of biomarkers has further stimulated the debate concerning population level screening for dementia (Prince, *et al.* 2011b). The impetus for this debate concerns the health care costs associated with the rising numbers of people living with dementia. For example Brodaty *et al.* (2011), identify that if we can postpone the clinical onset of dementia by 1 year, this would result in nearly 12 million fewer cases worldwide by 2050 and would lower healthcare costs.

While this debate will continue as new evidence emerges, population level screening is not currently recommended. The efficacy of biomarkers and other tests including neuropsychological assessments at this early stage is one reason why this is not considered to be practicable. Three other reasons support this decision.

Firstly, at the present time, although clinical trials are currently being undertaken to deliver interventions which may delay or prevent the onset of Alzheimer's disease or Vascular dementia; including MAPT (Gillette-Guyonnet, *et al.*, 2009), PreDIVA (Richard, *et al.* 2010) and FINGER (Mangialasche, *et al.* 2012), these are still in progress and results determining the efficacy of these interventions will not be available for some time. As a consequence, it is not known whether treatment of Alzheimer's disease pathology must begin before the clinical onset in order to be effective or what specific interventions are effective. Thus screening to detect people at risk at this early stage is unlikely to be acceptable or ethical (Furiak, *et al.*, 2012, Prince, *et al.* 2011b, Mattsson, Brax & Zetterburg, 2010).

Secondly, one study demonstrated that 81% of people surveyed in a particular primary care setting would want to be screened to identify if they are developing dementia, but indicated that this was in the context that treatment would be forthcoming should the results be positive (Hoslinger *et al.*, 2011). Furthermore, while screening for dementia might be acceptable, there are significant concerns about the potential harms arising from such screening. These harms include concerns about extended feelings of hopelessness arising from an early diagnosis, the impact of stigma associated with dementia, and the legal ramifications including the impact upon insurance premiums and mortgages (Mattsson, Brax and Zetterburg, 2010, Justiss *et al.* 2009). Thus as these authors suggest, significant attention would need to be paid to addressing these concerns as well as delivering effective interventions if population screening were to be implemented.

Finally, although early intervention is argued to be cost effective, economic calculations concerning early diagnosis and intervention do not currently factor in tests such as biomarkers or the service costs of population screening. The inclusion of such service delivery processes and tests is likely to significantly increase the costs of an early diagnosis (prior to clinical signs of dementia emerging) and would need to be addressed prior to advocating such a shift (Furiak, *et al.* 2012).

## **Conclusion**

Until research can confirm the efficacy of biomarkers or other methods of assessment to detect pre-clinical onset of Alzheimer's disease and other forms of dementia, and has developed reliable methods of intervening to prevent or delay the onset of such conditions, general screening is not recommended (Prince *et al.* 2011b). These authors indicate that even in higher income countries, the current point at which diagnosis occurs is most commonly at a later stage in the person's experience of dementia. As an emerging body of evidence exists for interventions at an early and timely stage (once

clinical signs have emerged) opportunistic or targeted screening within primary care and other health care settings may be a more appropriate strategy at this point in time (Prince *et al.* 2011b, De Lepeleire, *et al.* 2008).

## Section 2: Diagnosis at Time Point 2, Early Cognitive Changes

### Differential Diagnosis

Mild cognitive impairment (MCI) is currently the most widely recognised term for people who are experiencing early cognitive difficulties outside of that which would be expected in normal ageing, but are not severe enough to warrant a diagnosis of dementia. Whilst MCI as a construct has been used for the past decade across both research and clinic settings, there have not, until recently (Albert *et al.* 2011), been any established consensus guidelines for diagnosing MCI (Brooks & Loewenstein, 2010; Matthews, Stephan, McKeith, Bond, & Brayne, 2008; Ritchie, Artero, & Touchon, 2001). Thus, specific guidelines around what constitutes a cognitive deficit and where the boundaries should be between normal ageing, MCI and dementia have been lacking, with most clinics and researchers relying on individual clinical judgement to make this distinction (Budson & Solomon, 2012; Portet *et al.*, 2006).

It is generally agreed that MCI refers to a subjective and objective cognitive or memory deficit, intact functional abilities and the absence of a dementia (Bruscoli & Lovestone, 2004; Frank & Petersen, 2008; Winblad *et al.*, 2004). To date, the most frequently used cognitive screening test to aid with diagnosing MCI has been the Mini-Mental State Examination (MMSE; Folstein, Folstein & McHugh, 1975) (Cullen, *et al.*, 2006; Hodson & Keady, 2008; Levey, *et al.*, 2006). However, this test has been criticised for not including all key cognitive domains (Cullen *et al.*, 2006) and it has been suggested that the MMSE lacks sensitivity in identifying people with MCI (Hodson & Keady, 2008; Levey *et al.*, 2006). At present, no single test has been identified in the literature which has been recommended for the screening of MCI, with most researchers recommending that further research into suitable measures is necessary, suggesting alternative or additional tests such as the Montreal Cognitive Assessment (MoCA; Nasreddine *et al.*, 2005), which has been shown to have better sensitivity to MCI than the MMSE (Hodson & Keady, 2008), and warning against clinicians becoming over reliant on the MMSE (Cullen *et al.*, 2006).

The issue of functional ability has also been debated considerably in recent years, with a shift towards considering difficulties with functional abilities as acceptable in terms of the criteria for MCI (Dean & Wilcock, 2012). There have been some concerns over this change in attitude, as preserved functional abilities was previously the key dimension

that separated MCI and dementia, with some authors suggesting that inclusion of people with impaired functional abilities under the MCI umbrella may lead to people with mild dementia being misdiagnosed (Morris, 2012). However, with increasing research suggesting that people with MCI do have impaired activities of daily living it has been suggested that people with MCI will generally have slight difficulties with complex activities of daily living (CADLs) and instrumental activities of daily living (IADLs) but should have preserved basic activities of daily living (BADLs) (Dean & Wilcock, 2012, Pedrosa *et al.*, 2010).

The first set of consensus guidelines for MCI have been developed integrating some of the advances in research concerning MCI (Albert *et al.* 2011). A further set of consensus guidelines concerning Vascular Mild Cognitive Impairment (VaMCI) have also been developed (Gorelick *et al.*, 2011).

The guidelines by Albert *et al.* (2011) represent the second of 3 stages of consensus guidance concerning the diagnosis Alzheimer's disease, and indicate that in order for MCI to be 'diagnosed' there should be:

- Evidence of a change in cognition compared with previous functioning;
- Lower performance in one or more cognitive domains that is greater than would be expected for the patient's age and educational background, including memory, executive function, attention, language and visuo-spatial skills;
- Decline in performance should be evident over time;
- Preservation of independence in functional abilities, although abilities may be altered, and the person may be less efficient at normal activities of daily living;
- Insufficient impairment for a diagnosis of dementia.

(Albert *et al.* 2011)

These guidelines include further criteria for the establishment of a diagnosis for research purposes as well as for clinical practice. The consensus guidelines for VaMCI in addition to the above, specifically address the need to identify vascular pathology and to be able to establish a link between this and the onset of cognitive changes (Gorelick, *et al.* 2011).

In order to support a diagnosis of MCI, research has progressed towards considering the utility of neuroimaging and biomarkers, suggesting that: measuring tau protein levels and amyloid-beta levels in cerebrospinal fluid (CSF) (Brooks & Loewenstein, 2010; Budson & Solomon, 2012; Levey *et al.*, 2006) and changes in brain structure, such as hippocampal atrophy and other neuropathologic changes evident on neuroimaging

scans including magnetic resonance imaging (MRI), computerised tomography (CT) and flurodeoxyglucose positron emission tomography (FDG-PET) (Budson & Solomon, 2012; Fennema-Notestine *et al.*, 2009; Maioli *et al.*, 2007; Rossi *et al.*, 2007; Visser *et al.*, 1999) may enable more accurate identification of people with MCI than relying on neuropsychological tests and clinician judgement alone. However, despite these promising findings with regards to physiological differences between age-matched people with no cognitive impairments, people with MCI and people with dementia in research, the recommendation for clinical practice from those developing the guidance and others; is that the majority of these measures should not routinely be undertaken with people presenting with cognitive concerns (McKhann, *et al.* 2011, Budson & Solomon, 2012).

The differences in the methods used to identify people with MCI has led to MCI being an unstable diagnosis, with people with MCI representing a heterogeneous population (Prince, *et al.* 2011, Levey *et al.*, 2006; Palmer, Musicco & Caltagirone, 2010; Portet *et al.*, 2006). Studies investigating prevalence and incidence rates of MCI find varied results, and various studies suggest differing outcomes for people with MCI over time (Forlenza *et al.*, 2009; Levey *et al.*, 2006; Matthews *et al.*, 2008; Mitchell & Shiri-Feshki, 2009; Palmer *et al.*, 2010). Whilst it has been generally agreed amongst researchers and clinicians alike that people with MCI are at an increased risk of developing dementia compared to the general population (Bondi *et al.*, 2008; Kaduszkiewicz *et al.*, 2010; Rogalski *et al.*, 2009), the exact details of who is most at risk and how to identify these people remains unclear (Matthews *et al.*, 2008; Palmer *et al.*, 2010; Ringman *et al.*, 2009; Stephan *et al.*, 2007).

While guidelines now exist, further research in this area is needed in order to establish their sensitivity and specificity around diagnosing MCI if it is to continue to be used as either a research or clinical diagnosis in order to reduce the heterogeneity inherent in MCI at present. Alongside the consensus surrounding diagnostic criteria, it is also important that specific screening tools are developed or identified which are sensitive to MCI and able to detect mild cognitive deficits. Research continues to explore biomarkers and neuroimaging which may enable the identification of people most at risk of developing dementia, but as indicated above, it is recommended that these methods should not be extended to clinical practice at the current time for various reasons, including the ethical implications of screening for biomarkers (McKhann, *et al.* 2011, Budson & Solomon, 2012, Mattsson, Brax and Zetterberg, 2010).

## **Diagnostic Classifications**

Four key subtypes of MCI have been identified:

1. Amnesic MCI single domain (aMCI-SD; memory impairment only),
2. Amnesic MCI multiple domain (aMCI-MD; main impairment in memory, but also impaired in other cognitive domains),
3. non-amnesic MCI single domain (naMCI-SD; single impairment in a cognitive domain other than memory),
4. non-amnesic MCI multiple domain (naMCI-MD; impaired in multiple cognitive domains, but no memory impairment)

(Albert, *et al.* 2011, Gorelick, *et al.* 2011, Bondi *et al.*, 2008; Brambati *et al.*, 2009; Petersen & Morris, 2005).

A number of papers suggest that these subtypes of MCI have different outcomes, with aMCI-MD most frequently progressing to Alzheimer's disease (AD) and vascular dementia (VaD) (Hodson & Keady, 2008; Rossi *et al.*, 2007; Teng, Tingus, Lu & Cummings, 2009). People with naMCI-SD may be at an increased risk of progressing to frontotemporal dementia (FTD) (Rossi *et al.*, 2007) but also may be the most likely to revert to normal (Bondi *et al.*, 2008). naMCI-MD most commonly progresses to a non AD dementia (Bondi *et al.*, 2008), although studies report some variability in the outcomes for MCI subtypes, and one article suggests that aMCI-SD and aMCI-MD may actually be differing stages of a progression to AD (Brambati *et al.*, 2009).

However, despite the potential utility of these subtypes in terms of identifying people at risk for certain dementias, numerous difficulties have been identified in making a differential diagnosis by subtype. For example, it has been shown that failing to appropriately quantify all cognitive domains (Bondi *et al.*, 2008) and inconsistent use neuropsychological tests (Hodson & Keady, 2008; Lonie, *et al.*, 2008) may lead to erroneous subtype classification. There has also been considerable debate as to whether sub-typing MCI adds anything to the diagnosis, as MCI subtypes have been shown to be unstable over time (Bondi *et al.*, 2008; Matthews *et al.*, 2008) Several studies suggest that these subtypes are not useful in predicting progression to different dementias over time (Fischer *et al.*, 2007; Matthews *et al.*, 2008). A key issue in the research around subtypes of MCI is that there has been an almost exclusive focus on amnesic MCI (aMCI) and consideration of whether this subtype may progress to AD, with a paucity of research attempting to consider other subtypes of dementia or MCI (Petersen, 2009; Rossi *et al.*, 2007).

To date, sub-typing MCI has not shown to be of any clinical benefit, as research studies still disagree on the outcomes for differing MCI subtypes, so making a diagnosis of MCI by subtype in a clinic setting would not add anything at present to the diagnosis as no further prognostic information would be able to be provided according to subtype.

Whilst characterising MCI by subtype may prove to yield more information about people most at risk of progressing to dementia and may enable identification of the most likely outcome, further research is needed to achieve this, and at present it seems unhelpful to classify people with MCI by subtype in clinical practice.

### **Criteria for diagnosis in each of the diagnostic subtypes**

Currently there are no clear guidelines for diagnosis by subtype, with researchers and clinicians utilising different definitions, neuropsychological tests and cut-off values (Hodson & Keady, 2008; Matthews *et al.*, 2008). Recent research suggests that differentiating MCI subtypes relies on in-depth neuropsychological testing (Levey *et al.*, 2006), as different cognitive domains are affected in each subtype and thus testing which examines multiple cognitive domains is essential to identify MCI by subtype (Bondi *et al.*, 2008; Cullen *et al.*, 2006; Levey *et al.*, 2006). It has also been suggested that utilising laboratory examinations, such as investigating biomarkers and neuroimaging may assist with identifying MCI subtypes as it enables the underlying etiology of the cognitive difficulties to be ascertained (Albert *et al.*, 2011).

### **Who presents at each stage and what are they presenting with, what are the issues influencing this?**

By definition, people with MCI experience mild cognitive difficulties. As such, people with MCI will generally present with concerns about their memory or thinking and will have slight difficulties in one or more cognitive domain, but have relatively unimpaired functional abilities. That is, people with MCI can normally still undertake most activities of daily living but may struggle with more complex ones (Dean & Wilcock, 2012; Pedrosa *et al.*, 2010).

#### ***Who do they present to?***

People with MCI are most likely to present to their family doctor in the first instance, with family doctors then making the decision about whether to refer on to secondary, specialist services for diagnosis (Hodson & Keady, 2008; Kaduszkiewicz *et al.*, 2010). The prevalence rate of MCI is 3%; therefore approximately 1.5 million people in the UK are estimated to have MCI (Dean & Wilcock, 2012). It has been suggested however, that very few people are referred on to specialist services (Matthews *et al.*, 2008).

#### ***How long before presenting (factors influencing this)***

There is a paucity of research available which attempts to identify how long it takes for people first experiencing cognitive concerns (possible MCI) to present to their family doctor. One European wide study by Jones and colleagues (2010) suggests that the

average time for an person to contact their family doctor following first concerns is nearly a year (approximately 43 weeks), though this time period varies considerably between countries. This study also aimed to identify factors which influenced the time it took people to make contact with their family doctor, and they found that many people delayed making contact until they were sure that the symptoms were permanent, and not just a temporary issue. Informant reports also suggested that many people with subjective memory concerns and their family members maintained a belief that the symptoms they were noticing were just a part of normal ageing, failing to understand the severity of the symptoms either intentionally or unintentionally, and thus believed it was not worth bothering a physician with. The authors also found that people were quick to attribute the cause of their cognitive difficulties to other medical conditions, again believing that the symptoms were not particularly severe. Finally, this study revealed that a number of people delayed presentation to a family doctor because of the fear of being given a diagnosis of AD (Jones, *et al.*, 2010).

#### ***What process should be delivered and by who?***

Overwhelmingly in the literature, the consensus appears to be that primary care services should be better equipped to detect, people with cognitive impairment (Kamenski *et al.*, 2009; Mitchell, Meader, & Pentzek, 2011). However, recent studies have suggested that family doctors struggle to recognise MCI, and are prone to attributing memory problems to be an early sign of dementia (Kaduszkiewicz *et al.*, 2010). Studies have also shown that family doctors do not tend to carry out diagnostic work or follow-up for people with cognitive impairment after their first presentation, which may mean that people who have an underlying illness go undiagnosed, and untreated (Belmin, *et al.*, 2012). It is generally recommended that family doctors should refer people with suspected MCI to specialist services for more in-depth assessment (Hodson & Keady, 2008; Levey *et al.*, 2006). If people are identified as having MCI, then literature indicates that they should be monitored regularly due to their increased risk for developing dementia, although who should provide this monitoring is not specified (Levey *et al.*, 2006). Alongside this monitoring programme, it has been highlighted that the importance of healthy living should be stipulated to people with cognitive impairment as, whilst this area still requires further study to demonstrate concrete evidence for the benefits of exercise and a healthy diet in terms of cognition, some of the literature suggests that there are some potentially significant benefits achieved from making these lifestyle changes (Bondi *et al.*, 2008; Palmer *et al.*, 2010) and given that there is little risk in promoting a healthier lifestyle, this may be the best intervention that family doctors can offer to people with MCI at present (Chertkow, 2006).



However, with the lack of treatment options available for people with MCI, and the lack of prognostic information that clinicians can provide, there has been extensive debate over whether it is acceptable to disclose a diagnosis of MCI to a person at all. This is a debate which has yet to reach a conclusion, and further research is required in order to better understand how people react to a diagnosis of MCI and whether a diagnosis should be given. Of the literature that is available, studies have found that disclosure of an MCI diagnosis did not provide the same relief experienced by people when given a diagnosis of dementia, due to the questions that remain unanswered (Banningh, *et al.*, 2008). Furthermore, diagnoses that were perceived as “ambiguous” could result in people worrying about the cause of their cognitive concerns (Dean & Wilcock, 2012). The recent research by Banningh and colleagues (2008) suggest that there are clear disadvantages with giving a diagnosis of MCI, but the authors do not imply that the diagnosis should not be used; however, they call for caution when providing an MCI diagnosis, suggesting that specific and detailed MCI information should be provided to people and their families following a diagnosis (Banningh *et al.*, 2008). Several studies suggest that people experience confusion inherent with a diagnosis of MCI (Dean & Wilcock, 2012; Garand, *et al.*, 2009) and warn that clinicians should be aware of the confusion that can be caused with an MCI diagnosis, and that they should strive to make the diagnosis as unambiguous as possible, being sensitive to the fact that people with MCI are faced with prognostic uncertainty (Lingler *et al.*, 2006). Overall, there are a number of ethical issues to consider and research investigating these issues is still scarce. Given this lack of knowledge, Garand and colleagues (2009) suggest that MCI should be viewed as a research diagnosis rather than a clinical diagnosis, allowing for further research to be conducted to enable a better understanding of the impact of MCI diagnosis (Garand *et al.*, 2009).

### **What are the key challenges facing the practitioner / person / family at this stage?**

#### ***Lack of reliable methods of assessment***

Although diagnostic classifications for MCI are now available and furthermore are likely to be included in DSM-V and ICD-11 as Mild Cognitive Disorder, research is still required to develop appropriate, reliable and valid ways of detecting MCI in clinical practice (Eschweiler, *et al.* 2010). Without a clear set of screening tools, scoring guidelines and ranges, people who are given a diagnosis of MCI will remain a heterogeneous population, as diagnosis currently depends heavily on the judgement of individual clinicians, with each clinician preferring to use different, and potentially inaccurate, screening tools (Matthews *et al.*, 2008). Furthermore, the prevalence of people with MCI in any given primary care practice makes identification a particular challenge to

practitioners who already experience difficulties associated with detecting the early signs of dementia in their patients (Mitchell *et al.* 2011). Mitchell *et al.* found that family doctors were able to identify less than half of people with early dementia or MCI, thus the risk of false positive or false negative identification is high.

### ***Diagnostic Disclosure***

One of the most pertinent challenges facing all parties is the issue of diagnostic disclosure, and whether MCI should be used as a clinical diagnosis. At present, there has been little research conducted into understanding the impact of a diagnosis of MCI (Mattsson, Brax & Zetterberg, 2010), but the few studies that have been carried out suggest that people with MCI experience difficulties because of a lack of information concerning prognosis and as a consequence face an uncertain future (Banningh *et al.*, 2008; Dean & Wilcock, 2012; Lingler *et al.*, 2006). This is an area which requires more research in order to establish how people react to a diagnosis of MCI and to consider the implications of this for clinical practice.

### ***Information and Awareness Raising***

Information provision also needs to be addressed as many authors have suggested that, given the ambiguity of a diagnosis of MCI, providing comprehensive information to the person with MCI and their family is necessary (Banningh *et al.*, 2008; Dean & Wilcock, 2012). It has also been suggested that it is important to raise awareness of MCI both in the general public and amongst family doctors in order to increase the number of people presenting for assessment and to help people digest the diagnosis of MCI if it is given (Dean & Wilcock, 2012). However given the state of knowledge currently, available information is conflicting and ambiguous and thus potentially unhelpful to families.

### ***Service Provision***

Another key issue facing both practitioners and people with MCI and their families is the lack of appropriate treatment options and support services. A number of studies have identified that people feel very uncertain after being given a diagnosis of MCI (Banningh *et al.*, 2008; Dean & Wilcock, 2012; Lingler *et al.*, 2006) and feel that they have nowhere to turn, with many services discharging people with MCI following diagnosis with no treatment and limited information about MCI. It is suggested that early diagnosis should be combined with intervention, and follow up to identify those who progress to dementia, thus diagnosing people with MCI also requires a shift in service delivery systems in order that people with this diagnosis and their families are supported

(Werner & Korczyn, 2008, Hodson & Keady, 2008, Eschweiler, *et al.*, 2010, Leung, *et al.* 2011).

## **Conclusions**

In conclusion, MCI is a diagnostic construct which has been shown to have some promise in identifying people at risk of developing dementia. It seems likely that it will be incorporated into DSMV in 2013 under the categorisation of minor neuro-cognitive disorder (George, Whitehouse & Ballenger, 2011). However there is a clear need for further research in this area in order to determine the utility of MCI subtypes and whether it is possible to identify, with accuracy, those people who are most at risk of developing specific types of dementia. Furthermore, if MCI is to be used in clinical practice, then the development of appropriate assessment methods including screening tools to be utilised when making a diagnosis and scoring guidelines for these tools in order to reduce the variability across MCI samples is essential (Bondi *et al.*, 2008; Matthews *et al.*, 2008; Teng *et al.*, 2009).

There is still an ongoing debate surrounding MCI as a clinical diagnosis, with researchers highlighting the uncertainty experienced by people given a 'diagnosis' of MCI and questions emerging around whether it is ethical to give this 'diagnosis' whilst there is still so little prognostic information, no recommended treatment for people with MCI and an absence of service provision. While it has been suggested that detecting MCI in clinical settings enables monitoring of people who have been identified as being at high-risk for developing dementia (Levey *et al.*, 2006), studies have found that this monitoring of people with MCI is lacking at present (Belmin *et al.*, 2012).

Therefore, it is essential, if MCI is used as a clinical diagnosis, that appropriate information is available and provided to people who are informed that they have MCI, including information about where to access support, so that they can better cope and understand MCI more fully. Thus service systems also need to adjust to provide a care pathway following disclosure, incorporating the provision of regular follow up and psycho-social interventions for people with MCI and their families. Such systems need to be informed by further research exploring the impact and experience of MCI, the advances in detection and treatment and the interventions that would be most effective in supporting people with MCI and their families.

## Section 3: Diagnosis at Time Point 3: Early and Timely Diagnosis

### Introduction

Research has highlighted that many people do not ever receive a diagnosis of dementia and that furthermore, where a diagnosis does occur, it is frequently much later in the experience of dementia, when clinical signs have progressed and activities of daily living, cognition, relationships, behaviour and quality of life are already significantly challenged (Bamford, *et al.*, 2004, Carpenter & Dave, 2004, Prince *et al.* 2011b). In response to this, a number of countries have set targets within their dementia strategies for early diagnosis, for example the Department of Health in England identified that a core aim is “*to ensure that effective services for early diagnosis and intervention are available for all on a nationwide basis*” (Department of Health, 2009: 33). However it is necessary to define clearly what is meant by early as opposed to later diagnosis given such issues as the current debate concerning diagnosis and interventions in the prodromal (pre-clinical) phase of Alzheimer’s disease.

Prince *et al.* (2011b: 12) define a four-stage timeline of disease progression:

1. Time point one (T1), neuropathology but no clinical signs, is the earliest possible point of diagnosis if reliable biomarkers are developed;
2. Time point two (T2), neuropathology, early cognitive changes and possible disability, subjective impairment and help seeking, earliest possible diagnosis using currently available technology;
3. Time point 3 (T3), onset of cognitive decline and disability, subjective impairment and/or help seeking, focus on timely diagnosis, responding to patient and carer concerns rather than proactively screening for the disease;
4. Time point 4 (T4), significant evidence of cognitive decline and disability, help seeking, current late stage diagnosis.

As indicated in an earlier section of this review (population screening), diagnosis at time point 1 is currently not recommended as reliable biomarkers are needed as well as effective interventions. There are also particular challenges evident for service systems in achieving a diagnosis at time point 2, which would need to be addressed if we are to respond effectively to need, for example primary care detection at this early stage currently risks a high rate of false positive identification (Mitchell, *et al.* 2011). Thus Prince *et al.* (2011b) suggest that our aim is “*to advance the time at which the diagnosis is made to the earliest stage possible*” (12). However they qualify this by recognising that these processes should also include the perspectives of people with dementia and their families when defining early diagnosis. Many dementia strategies emphasise the capacity of early diagnosis to provide the foundations for living well with dementia,

including having information, opportunities to adapt and maintain valued life experiences and making plans for the future (Department of Health, 2009, Norwegian Ministry of Health and Care Services, 2006, 3<sup>rd</sup> French National Plan for Alzheimer and related diseases, 2008). Living well with dementia importantly involves a process of psychological and emotional adjustment, in which the person and their family are able to make choices and have control over the process of assessment, disclosure and receipt of post-diagnostic support, information and interventions (Moniz-Cook, *et al.* 2006, Derksen, *et al.* 2006, Betts & Cheston, 2012, De Lepeleire *et al.* 2008. Stokes, Combes & Stokes, 2012). These authors have highlighted the significant challenges facing the person and their family in undergoing assessment, not least of which is the stigma associated with dementia, fears for the future and support following diagnosis. Thus in order to facilitate a process of adjustment and adaptation, it is proposed that early diagnosis should also be timely diagnosis, occurring at a point when the person and their family are ready to undergo assessment (De Lepeleire, *et al.* 2008).

Thus early and timely diagnosis requires a sensitive and staged approach to assessment which begins at detection of difficulties, followed by a comprehensive assessment; a sensitive process of diagnostic disclosure and following this, early intervention (De Lepeleire, *et al.* 2008, Prince, *et al.* 2011b, Koppel & Dallos, 2007, Stokes, Combes & Stokes, 2012). These processes will now be addressed in subsequent sections, beginning with considering the diagnostic classification of dementia and differential diagnosis.

### **Diagnostic Classification of Dementia Syndrome**

Two primary sources of diagnostic classification have been available to assist in clinical diagnosis of dementia syndrome, ICD-10 (International Classification of Diseases version 10, 1993) and DSM-IV (diagnostic and statistical manual of mental health disorders version 4, 1994).

The ICD-10 classification required evidence of:

1. A decline in memory, which is most evident in the learning of new information, although in more severe cases, the recall of previously learned information may be also affected;
2. A decline in other cognitive abilities characterized by deterioration in judgement and thinking, such as planning and organizing, and in the general processing of information;
3. Preserved awareness of the environment (i.e. absence of clouding of consciousness);
4. A decline in emotional control or motivation, or a change in social behaviour;

5. For a confident clinical diagnosis, 1 should have been present for at least six months; if the period since onset is shorter than this, the diagnosis can only be tentative;
6. The diagnosis is further supported by evidence of damage to other higher cortical functions, such as aphasia, agnosia and apraxia.

DSM-IV differs slightly from ICD-10, identifying that memory plus one other cognitive domain should be affected in order to achieve a diagnosis of dementia, whereas ICD-10 indicates that memory, abstract thinking, judgement and problem solving should be affected as well as one further cognitive domain (Lopez *et al.* 2011). Criticisms of ICD-10 and DSM-IV have included concerns about sensitivity; being less likely to detect dementia at an early stage (ICD-10) (Lopez *et al.* 2011); low specificity for probable AD (Waldemar, *et al.* 2007b); being overly descriptive (DSM-IV) (Sachdev, *et al.* 2009); missing those who do not have memory as a primary impairment (Lopez, *et al.* 2011) and more recently that advances in the assessment, pathology and etiology of dementia result in the need for further revisions of criteria (Eschweiler *et al.* 2010, Jack, *et al.* 2011). DSM-V and ICD-11 are currently under development and are expected to become available in 2013 and 2015 respectively.

#### ***NIA-AA All Cause Dementia***

More recently, with the revision of the diagnostic guidelines specifically developed for the varying stages of Alzheimer's disease (Jack, *et al.* 2011, McKhann, *et al.* 2011) an all cause criteria for dementia has been developed (McKhann *et al.* 2011). These criteria were developed to respond to the criticisms of previous criteria including those mentioned above. In addition the authors aimed to provide family doctors with the tools to make a simple diagnosis by incorporating descriptions of each domain as well as making these criteria relevant to researchers (McKhann, *et al.* 2011, Lopez *et al.* 2011, Budson & Solomon, 2012). In this set of criteria, dementia is understood to be present where there are cognitive or behavioural symptoms that:

- Interfere with the ability to function at work or at usual activities and;
- Represent a decline from previous levels of functioning and performing and;
- Are not explained by delirium or major psychiatric disorder; and
- The cognitive or behavioural impairment involves a minimum of two of the following domains:
  - Impaired ability to acquire and remember new information
  - Impaired reasoning and handling of complex tasks including poor judgement

- Impaired visuo-spatial abilities
- Impaired language functions
- Changes in personality, behaviour or demeanour

(McKhann, *et al.* 2011; 3)

While these are relatively new criteria and are believed to require further validation, much of the debate surrounding their efficacy appears to relate to the specific criteria for preclinical Alzheimer's disease and MCI and in particular the recommendation of the use of biomarkers (Frisoni, Winblad & O'Brien, 2011). The authors of these criteria highlight that at this current point in time, the use of biomarkers should be restricted to research (McKhann, *et al.* 2011, Albert, *et al.* 2011, Jack *et al.* 2011). It is nevertheless believed by some that the all cause criteria are of clinical utility at the present time, despite needing further validation (Budson & Solomon, 2012).

### **Diagnostic Classifications and Criteria for Dementia Subtypes**

The main subtypes of dementia are listed below, although many more are thought to occur but with much less frequency (Knapp & Prince, 2007, Alzheimer's Disease International, 2009). These are:

- Alzheimer's disease (AD)
- Vascular Dementia
- Dementia with Lewy Bodies and Parkinson's disease dementia
- Fronto-temporal dementias (FTD)

Alzheimer's disease is the most common form of dementia, affecting 62% of people with a diagnosis, with Vascular Dementia the next most common affecting 16% of people who have dementia. 10% of all people who have dementia have a mixed pathology, with 6% having Dementia with Lewy Bodies or Parkinson's disease dementia. Finally 2% have Fronto-temporal dementias (Knapp & Prince, 2007). AD and FTD can be further divided into different presentations as follows:

#### ***Alzheimer's disease (AD)***

- Amnesic (Primary impairment in memory plus at least one other cognitive impairment)
- Executive dysfunction (Primary impairment in reasoning, judgement and problems solving)
- Posterior Cortical Atrophy (PCA) (Primary impairment in spatial cognition)

- Language presentation (Primary impairment in word finding)  
(McKhann, *et al.* 2011, Snowden, *et al.* 2011)

### ***Fronto-temporal Dementias (FTD)***

- Behavioural variant FTD
- Semantic Dementia
- Progressive non-fluent aphasia  
(Rascovsky, *et al.* 2011, Gorno-tempini, *et al.* 2011)

While there are different subtypes of Vascular Dementia, including cortical vascular dementia and subcortical ischaemic vascular dementias such as CADASIL (Gorelick, *et al.*, 2011, Benisty *et al.* 2008) precise diagnosis of all types remains complex (Wiederkehr, *et al.* 2008a, Wiederkehr, *et al.* 2008b). Less common subtypes of dementia include the following:

- Progressive Supranuclear Palsy
- Creutzfeldt Jacob Disease
- Wernike Encephalopathy and Korsakoffs Syndrome (caused by Vitamin B deficiency, which occurs in Alcohol misuse)
- HIV-related cognitive impairment
- Huntingdon's disease

Both DSM-IV and ICD-10 have criteria for subtypes of dementia, however these have not been designed for use as diagnostic criteria, and problems have been identified in using them in this way (Gorelick, *et al.* 2011). Specific sub-type diagnostic criteria have been developed and used over the past 30 years. These include the NINCDS-ADRA criteria for Alzheimer's disease (McKhann, *et al.* 1984); Fronto-temporal lobar dementia criteria (Neary, *et al.* 1998) and the NINDS-AIREN for Vascular Dementia (Román, *et al.* 1993). However there are a number of criticisms of these criteria involving sensitivity and specificity (Waldemar, *et al.* 2007a, Piguet, *et al.* 2009) and the advances described earlier, that have occurred since these were published. Consequently, in recent years diagnostic criteria have been developed for the main subtypes listed initially. Some of these have been developed using international experts and are believed to require further validation and possibly revision to assure their specificity and sensitivity (McKhann, *et al.* 2011, Rascovsky, *et al.* 2011, Gorelick, *et al.* 2011).

These criteria are as follows:



- Alzheimer's disease, (Pre-clinical, MCI and Alzheimer's disease) National Institute on Aging and the Alzheimer's Association Workgroup, McKhann *et al.* (2011) (replacing NINCDS-ADRA, McKhann, *et al.* 1984);
- Vascular Dementia, Vascular contributions to cognitive impairment and dementia: a statement for Healthcare Professionals from the American Heart Association/American Stroke Association (Gorelick, *et al.* 2011) (replacing NINDS-AIREN, Román *et al.* 1993, and ADDTC, Chui *et al.* 1992);
- Behavioural Variant Frontotemporal Dementia; revised diagnostic criteria (Rascovsky, *et al.* 2011) (replacing Manchester- Lund criteria, Neary *et al.* 1998);
- Dementia with Lewy Bodies (McKeith, *et al.* 2005, Macijauskiene & Lesauskaite, 2012);
- Parkinson's disease dementia (Goetz, Emre & Dubois, 2008, Emre *et al.* 2007);
- Vascular Dementia with CADASIL (NINDS-AIREN revised criteria, see Benisty, *et al.* 2008);
- Semantic Dementia and Progressive Non Fluent Aphasia (Gorno-tempini, *et al.* 2011) (replacing Manchester- Lund criteria, Neary *et al.* 1998).

### **Differential diagnosis**

While considerable advances have occurred in the etiology and pathogenesis of dementia, the diagnosis of these different conditions can be complex in clinical practice (Mahlberg, 2010, Waldemar, *et al.* 2006, Snowden, *et al.* 2011). The diagnosis of dementia involves a complex interplay between the results of assessment and diagnostic processes and knowledge of the person's personality, level of functioning and history (Milne, 2010). It also involves recognising that significant individual variability in the experience of symptoms is evident (Iliffe & Drennan, 2001). Thus differential diagnosis involves a holistic approach to the person, gaining information through a range of methods, and importantly, involving the person and their family throughout the process.

Traditionally, a two stage approach is undertaken in diagnostic evaluation, firstly to determine whether the person has dementia, and secondly, to define etiology; the subtype of dementia that may be present (Eschweiler, *et al.* 2010, Lopez, *et al.* 2011). Differential diagnosis at stage one seeks to identify if a dementia diagnosis is the most likely conclusion and involves ruling out other possible conditions that may be the cause of the cognitive difficulties, including treatable causes of cognitive impairment. Stage 2 involves distinguishing between different subtypes of dementia.

Currently the following steps are recommended for achieving differential diagnosis:

1. Ascertaining the person's own description of symptoms and history and also history from a significant other in the person's life. Such history taking should include:
  - a. Mode, duration and speed of onset of changes
  - b. Impact upon activities of daily living
  - c. Past medical history,
  - d. Family history and
  - e. Educational history
2. Neurological, psychiatric and general medical examination, which should:
  - a. Rule out co-morbidities including:
    - i. Delirium (Davies, *et al.* 2012)
    - ii. Neurological conditions including Huntingdon's disease (Snowden, *et al.* 2011)
    - iii. Mental Ill Health including Depression (Eschweiller, *et al.* 2010, Kelley, Boeve & Josephs, 2009, Rapp *et al.* 2011)
  - b. Identify neurological or vascular symptomatology

This examination should also include:

  - a. Blood Screening for VitB12, Folate, TSH, Calcium, Glucose, FBC, Renal and Liver Function, ESR, Cholesterol, Electrolytes, (with further tests if history/ clinical opinion suggestive of other factors)
  - b. Urine screening
3. Psychiatric examination which should include:
  - a. History of mental ill health
  - b. Assessment of current mood
  - c. Assessment for the presence of neuropsychiatric symptoms such as hallucinations, changes in personality and behaviour
4. Assessment of cognitive function which should include appropriate tests for:
  - a. Memory
  - b. Executive Function
  - c. Language
  - d. Visuo-spatial and visuo-constructive abilities

Further and extended neuropsychological testing should be completed where initial testing cannot provide a confident diagnosis.

5. Neuro-imaging is recommended in many clinical guidelines, for example the National Institute for Clinical Excellence (2006) indicates that all investigations for suspected dementia should include the use of structural MRI (Magnetic Resonance Imaging), however practice in this regard is variable. Computed tomography (CT) is also commonly utilised, although this is perceived to be less effective than MRI (Parsi *et al.* 2011). For differential diagnosis in a younger person with suspected dementia, FDG PET and SPECT can also be useful, for doubtful diagnosis and in order to differentiate between FTD and AD (Snowden, *et al.* 2011)
6. EEG is viewed as helpful in achieving differential diagnosis of atypical presentations of AD and CJD or other conditions
7. CSF analysis is recommended for Creutzfeldts Jacob Disease
8. ApoE4 testing is not recommended
9. Genetic testing is currently only recommended where evidence exists of a first degree relative with early onset dementia

(Budson & Solomon, 2012, Eschweiler, *et al.* 2010, Gorelick *et al.* 2011, Parsi, *et al.* 2011, Wattjes, 2011, Goetz, *et al.* 2008, McKhann, *et al.* 2011, Rascovsky, *et al.* 2011)

In order to achieve a differential diagnosis, there are further factors which require specific attention involving specific groups of people, and the methods utilised in the above categories. These are as follows:

***Younger people (below the age of 65)***

The diagnosis of dementia at a younger age is complex for a number of reasons. Firstly, it is acknowledged that the presentation of cognitive difficulties frequently takes a different form in younger people, with atypical presentations being significantly more frequent than in older people (Koedama, *et al.* 2010, Morhardt, 2011). For example, Koedama, *et al.* found that one third of younger people with dementia presented with non-memory symptoms compared with only six percent of older people. Secondly, these and other authors have highlighted that younger people are often misdiagnosed with psychiatric disorders which further highlights the differences in initial symptom experience between older and younger people (Morhardt, 2011, Kelley, Boeve & Josphehs, 2009). Thirdly, there is a higher prevalence of less common forms of dementia; including progressive supranuclear palsy and Huntington's disease; of dementia which is inherited and dementia caused through alcohol misuse (Alzheimer's Australia, 2007, Sampson *et al.*, 2004, Thomson *et al.* 2002). Finally, evidence points to the specialist nature of the assessment and diagnostic process with younger people, due to these particular complexities which may require a prolonged and highly specialist process of

assessment (Department of Health, 2009, Snowden, *et al.* 2011, Rosness, *et al.* 2008, van Vliet, *et al.* 2011). Thus younger people with dementia and their families frequently experience longer periods of time from first noticing symptoms to diagnosis (van Vliet, *et al.* 2011, van Vliet, *et al.* 2012)

### ***People with intellectual disabilities***

The increased risk of AD in people living with Down's syndrome (DS) due to genetic risk factors is widely recognised (Aisen *et al.* 2005; Zigman & Lott 2007). The onset of AD and other subtypes such as FTD begins at an early age in people with DS, in the fifth and sixth decades of life, with the average age of onset being mid 50's (Strydom *et al.* 2010). In recent years it is also recognised that as people are living with intellectual disabilities (ID) into older age, the prevalence of dementia among this population has also increased (Strydom *et al.* 2007, Strydom, *et al.* 2009, Whitwham & McBrian, 2011). Achieving a diagnosis of dementia in people with intellectual disabilities or Down's syndrome is complicated by the limitations of standard criteria and assessment processes used for adults without disability; different presentations of early signs of dementia; the level of cognitive difficulties experienced at baseline and the heterogeneity of the population (Burt *et al.* 2005, Strydom *et al.* 2007, Whitwham & McBrian, 2011). Research to develop appropriate criteria and assessment processes for people with ID or DS, and to understand the presentations, course and experience of dementia in this context are increasing. This research points to the need for specialist assessment, incorporating a thorough knowledge of the person and their life context; as well as their disabilities (Strydom, *et al.* 2010, Whitman and McBrian, 2011, Strydom, *et al.* 2007, Burt *et al.* 2005).

### ***Older people***

Older people experiencing dementia have a greater risk of mixed pathology, including the combination of a vascular and Alzheimer's pathology or DLB and Alzheimer's pathology which complicates diagnosis of specific subtypes (Ballard, *et al.* 2011, Snowden, *et al.* 2011, Dubois, *et al.* 2010). Older people also frequently experience co-morbidity, involving co-existing physical and mental health difficulties such as those listed above (Draper, *et al.* 2011, Rapp, *et al.* 2011). Assessment involves careful attention to those factors that might explain the presenting cognitive difficulties, including instigating treatment as appropriate and a more prolonged period of assessment where appropriate, involving follow up assessments before a diagnosis is made.

### ***People from migrant or indigenous minority communities***

The diagnosis of dementia in migrant or indigenous minority communities is complicated by a number of factors, including language use; conceptualisations of dementia and stigma (La Fontaine *et al.* 2007, Seabrooke & Milne, 2009, Tilki, *et al.* 2010) It is further complicated by patterns of help seeking which are frequently influenced by the cultural competence of health care systems in the host country including attitudes towards people from migrant or indigenous groups and the availability of appropriate assessment methods that respond to the specific needs of such communities (Tilki, *et al.* 2010, Neilson, *et al.* 2011a, Neilson *et al.* 2011b Neilson *et al.* 2011c). It is identified that as a consequence of these issues, the assessment and diagnosis of people from migrant and minority indigenous groups often fails to meet the needs of people living with dementia and their families in these communities, either misdiagnosing or missing altogether the presence of dementia. Differential diagnosis in these circumstances involves ensuring the use of appropriate assessment and diagnostic methods as well as culturally competent care in order to achieve a rigorous diagnostic outcome that also responds to the specific needs of the person and their family within their cultural context.

As indicated previously, the above issues point to the complexity involved in achieving a diagnosis of dementia at an early stage. They highlight the importance of achieving a diagnosis based upon appropriate criteria, and a comprehensive assessment methodology combined with a holistic approach. These next sections will address further factors that influence the delivery of early and timely assessment and diagnosis.

### **Who presents with early cognitive changes and what factors influence their contact with services?**

Evidence concerning who presents for initial consultation where a person has cognitive difficulties is limited, with most studies exploring the perspectives of those who might have dementia, and their family members using screening methodologies to access this population (e.g. Boustani, *et al.* 2006). In the early stages of dementia, while it might be assumed that it is more likely that the person experiencing symptoms would be the person to initiate help seeking; literature indicates that it is more complex than this. The process initially involves recognition by the person with symptoms that something might be wrong, a process which can take some time. During this time their family may also recognise changes which may then result in a process of negotiation, in recognising and confirming the difficulties followed by decision making by the person with symptoms and/ or their family members (Chrisp, Taberer & Thomas. 2012a, Chrisp *et al.* 2011, Manthorpe, *et al.* 2011, Leung *et al.* 2010, Koppel & Dallos, 2007). For example

Chrisp, Tabberer & Thomas, (2012a) illustrated that in their qualitative study the majority of initial contacts with health care professionals to initiate assessment were made by family members rather than the person with cognitive symptoms. However in other studies, the person with symptoms describes making the contact, but often with prompting from family members who were concerned and had noticed changes (Manthorpe, *et al.*2011, Leung, *et al.*2010, Koppel & Dallos, 2007). The literature points to important factors concerning help seeking and time to diagnosis.

Jones *et al.* (2010) reporting on the IMPACT study, found that family members reported the time from noticing symptoms to diagnosis ranged from 36 to 63 weeks. Chrisp, *et al.* (2011) indicates in their study that the mean journey time from first noticing symptoms to receiving assessment was three years. However, unlike the IMPACT study, their research included people with symptoms rather than solely family members. They identify that 75% of persons with symptoms noticed changes for just less than one year before speaking to a family member about it. Following this, the time before consulting a health care professional was one year and three months for 90% of the persons with symptoms and their family members. The literature in this area explores the reasons for the time before help is sought.

These reasons include; a gradual onset, and attribution of changes to normal ageing (Leung, *et al.* 2010, Boustani, *et al.* 2006, Jones, *et al.*2010, Chrisp, *et al.*2012b); or attributing difficulties to other health problems (Leung, *et al.*2010, Chrisp, *et al.*2012b, Jones, *et al.*2010); not recognising the severity of the difficulties and denial (Chrisp, *et al.* 2012b, Jones, *et al.* 2010); Stigma (Boustani, *et al.*2006, Leung, *et al.*2010, Iliffe & Manthorpe, 2004); unwillingness to approach a health care professional (Chrisp, *et al.*2012b, Jones, *et al.* 2010) the level of awareness and understanding of the difficulties being experienced (Leung, *et al.* 2010, Jones, *et al.* 2010) and finally living alone which contributed to lack of awareness (Lehmann, *et al.*, 2010). As Manthorpe, *et al.* 2011) identify,

*“Dementia is not something that suddenly happens to you; that you are suddenly a different person in need of help. It is a complicated and slow process of internal recognition and acknowledgement, external acknowledgement within families and relationships and finally a slow journey through health services” (p45).*

Furthermore, these studies illustrate the difficult emotional journey for the person and their family members, that run alongside this process, involving distress; disagreement and conflict; fear for the future; concerns about loss of self and identity and the experience of stress (Manthorpe, *et al.* 2011, Chrisp, *et al.* 2011, Chrisp, *et al.*2012b, Roseness, Ulstein & Engedal, 2009, Moniz-Cook, *et al.*, 2006). This complex emotional

journey can result in considerable challenges within the family context. While some families are able to work together to achieve a way forward, it is evident that such challenges can also result in the person with symptoms and their family members working apart or separately (Keady & Nolan, 2003, Chrisp, *et al.* 2012b). These responses can lead to help being sought without the agreement of the person with symptoms, possibly rendering the person with symptoms as passive and in need of protection. Alternatively although less commonly, the person with symptoms may seek help alone (Chrisp, *et al.* 2012b, Manthorpe, *et al.*, 2011).

It has been recognised that increasing the numbers of people coming forward for assessment and diagnosis and reducing the time before help is sought requires that the factors identified above are addressed through challenging the stigma associated with dementia. Additionally, these issues can be addressed through raising public and professional awareness and understanding; the provision of appropriate information and the identification of strategies which enable the difficult conversations about changes and help seeking to take place (Department of Health, 2009, Norwegian Ministry of Health and Care Services, 2006, 3<sup>rd</sup> French National Plan for Alzheimer and related diseases, 2008, Batsch & Mittleman, 2012). As consequence, many dementia strategies have explicitly identified targets to tackle such issues, including public and professional awareness campaigns, the provision of appropriate information through a variety of media including television and the internet and developing 'dementia friendly communities' (e.g. see for example Department of Health, 2012) .

Resources such as the internet are increasingly utilised by people and their families as a source of information about health concerns (Cherbuin, Anstey & Lipnicki, 2008). These authors have suggested that it is necessary to consider whether screening instruments could be an additional resource in increasing appropriate detection if made available on the internet for self or informant administration. While a number of concerns about the potential risks associated with self testing are evident including the validity and reliability of the tests and their administration; interpretation of results; increasing levels of anxiety; false positive testing and availability of information on resources and actions following a positive result, these authors identify that people are currently self testing without valid and reliable measures to draw upon (Cherbuin, Anstey & Lipnicki, 2008). Thus they argue that measures are needed and suggest that certain informant measures could be adapted for use in this way. Subsequently screening measures have been developed, including Test Your Memory (Brown, *et al.* 2009) and the Self-Administered Gerocognitive Examination (Scharre, *et al.* 2010); however literature evaluating the impact and effectiveness of such measures is not currently available.

As the discussion concerning factors influencing help seeking indicates, persons with symptoms and their families experience a complex process leading to the point at which they seek help from health care professionals. Literature identifies that in the majority of situations, the first contact is with a primary health care professional, usually a family doctor, either from a family member and/or the person with symptoms (Boustani, *et al.* 2006, Manthorpe, *et al.* 2011). However contact may also occur with other health or social care professionals who might already be involved for other health or social care needs, (although much less frequently) and the result of this is commonly advice to see their family doctor (Manthorpe, *et al.* 2011, Chrisp, *et al.* 2012b). Literature suggests that the consultation is not necessarily planned, and may reflect a combination of progression in symptoms resulting in undeniable changes; crises occurring, often as a result of progression in symptoms; other family members and carers agreeing a course of action without involving the person with symptoms and contacts with Health Care Professionals for other reasons, resulting in a discussion about the symptoms (Leung, *et al.* 2010; Chrisp, *et al.* 2012b).

The experience of assessment and diagnosis can be a defining moment in the experience of dementia, and may have a major impact on outcomes for the person and their family (Banerjee & Wittenberg, 2009, Moniz-Cook, *et al.* 2006, Koppel & Dallos, 2007) While some studies demonstrated that the subsequent process of assessment and diagnostic disclosure was a positive experience, others described difficulties throughout the process (Manthorpe *et al.* 2011, Moniz-Cook, *et al.* 2006, Koppel & Dallos, 2007, Dersksen, *et al.* 2006). It is necessary therefore to consider how people with symptoms experience the process of detection, assessment and diagnostic disclosure, and what actions can be taken to make the process responsive to the needs of the person and their family in addition to ensuring that a comprehensive medical assessment is achieved.

### **How can processes be responsive to the needs of people with dementia and their families?**

A recent systematic review explored the literature concerning the experience of diagnostic disclosure, bringing together the results of a number of qualitative studies (Manthorpe, *et al.* 2011). This review highlighted a number of issues concerning the experience of people with symptoms and their family members which are as follows:

- The process of assessment arriving at diagnosis is frequently lengthy and confusing. While some expected to be told that they have a diagnosis of dementia, others experienced this as a shock, although this is commonly associated with less awareness of symptoms;



- Family members in one study expressed concerns about negative attitudes from professionals and fragmented pathways to receiving a diagnosis;
- Concerns were expressed about the terms used, with Alzheimer's disease being associated with stigma;
- Distress was experienced at the point of disclosure by the person with dementia, although some also experience the diagnosis as a relief. Family members report that distress can be worse for the person with dementia in the days following disclosure;
- Younger people with dementia felt that they had not been prepared to hear the diagnosis. Other studies highlighted that people with dementia and their family members preferred a progressive process of disclosure, with some forewarning of the outcome;
- An individualised response was viewed as important as people varied in what and how they wanted to be told, with the reviewed studies achieve a consensus that diagnostic disclosure should be an ongoing process, with an emphasis on positive aspects of the person's life as well as providing tailored information and details of ongoing support;
- People with dementia and their families emphasise the need for a positive relationship with the health care professional who is disclosing the diagnosis, as well as the involvement of other professionals in the session, who can provide support following disclosure;
- Family members reported feeling let down by the lack of follow up after receiving a diagnosis. They also indicated the need for tailored information concerning disease progression and support services;
- People with dementia or MCI frequently did not retain the diagnosis, but were able to retain other information provided. Factors influencing this retention included stigma, negative attitudes and previous family experience of people with dementia;
- Cultural factors influenced diagnostic disclosure, including traditions of respect influencing willingness to seek help and the negative connotations of a diagnosis.

Many of the issues raised above have prompted discussion about the ways in which a person and family centred process of assessment and diagnosis can be delivered, including the development of guidelines for diagnosis assessment and disclosure (Derksen, *et al.* 2006, Delpeleire, *et al.* 2008, Doncaster, Hodge & Orrell, 2012, Cheston & Bender, 1999). These guidelines (Derksen, *et al.* 2006) and associated processes are described in brief below:

- Pre-assessment counselling should be provided, giving the person and their family tailored information about assessment processes and possible outcomes

thus enabling them to consider what implications this might have for them. This process also facilitates time to consider their psychosocial needs and how these might be met. Finally, pre-assessment counselling also creates opportunities for informed decision making. (Williams, 2004, Moniz-Cook *et al.* 2006);

- Psycho-social support from appropriate health care professionals should be provided, beginning with pre-assessment, and following the person through, ideally maintaining the relationship in order to provide psychosocial support following diagnosis (Moniz-Cook *et al.* 2006, Manthorpe, *et al.* 2011, Aminzadeh, *et al.*, 2007). Such support can facilitate a depth understanding of the person and their family in their psycho-social context, as well as creating opportunities to challenge the stigma associated with dementia, and identify ways in which support can be tailored to meet need;
- Steps 1 and 2 should also incorporate discussions about the person and their context in order that diagnostic disclosure can be tailored to their needs (Derksen, *et al.* 2006, Pratt & Wilkinson, 2003, Doncaster, Hodge & Orrell, 2012);
- Assessment needs to incorporate developing an understanding of the pre-existing relationship between the person with symptoms and their family member, as evidence suggests that such factors have significant implications for wellbeing and opportunities to live well with dementia following diagnosis (Ablitt, *et al.* 2009, Zarit, *et al.* 2010, Ablitt, *et al.* 2008, Czaja, *et al.* 2009);
- The same person involved in diagnostic assessment should deliver the diagnosis, preferably with the presence of the professional who has been involved in providing psycho-social support through the process of assessment (Derksen, *et al.* 2006);
- The disclosure session should occur with adequate preparation, including time, continuity in care, knowledge of the person's wishes concerning who should be present, what they wish to know and how they wish the information to be delivered (Derksen, *et al.* 2006, Doncaster, Hodge & Orrell, 2012, Elson, 2007);
- Disclosure should be clear and brief, avoiding jargon and euphemisms and followed up by the opportunity for questions and further information to be offered (Derksen, *et al.* 2006, Doncaster, Hodge & Orrell, 2012);
- Disclosure should also create time for emotions to be expressed and explored (Derksen, *et al.* 2006, Doncaster, Hodge & Orrell, 2012);
- Follow-up counselling and interventions should also be organised to create opportunities for the person and their family to discuss the news, express feelings, discuss care, information needs and support and identify further needs. This should also include assessment and interventions to address possible challenges in adjustment (Derksen, *et al.* 2006, Doncaster, Hodge & Orrell, 2012, Czaja, *et al.* 2009).

A number of other factors need to be considered when addressing early and timely diagnosis, including who delivers the process, where and when, and what factors might influence this delivery. These areas are now addressed.

### **Who do people with symptoms and their families receive early detection, assessment and diagnosis from, and what are the key challenges involved in delivering this?**

As has already been highlighted, people who experience cognitive changes which might lead to a diagnosis of dementia have diverse needs. Thus, the settings in which their difficulties are raised and assessment is considered are also diverse. While the majority will first approach their family doctor in primary care, this is not the only place where concerns might be noticed or raised (Boustani, Schubert & Sennour, 2007). As well as residing in their own home, people experiencing early changes may also be residing in a care home setting, or be identified when receiving care in an acute or rehabilitation setting related to other health care needs that may be present, although limited literature addresses the particular issues of identification, assessment and diagnosis in this context (Parke, *et al.* 2011, Nazarko, 2009, Zimmer, *et al.* 2010, Mukadam & Sampson, 2011).

Following the initial contact with a health care provider, much of the literature focuses upon two main providers of assessment and diagnosis, family doctors and their colleagues in primary care and the provision of specialist assessment and diagnosis, by neurologists, psychiatrists, geriatricians and specialist mental health services including memory clinics (Robinson, *et al.* 2010, Banerjee, *et al.* 2007, Morgan *et al.* 2009, Hean, *et al.* 2011, Ramakers & Verhey, 2011). Each of these providers will be addressed in turn, considering who is involved at this stage, where this is delivered, what factors influence delivery and what they deliver.

#### ***Family Doctors and Primary Care***

Most commonly, the first point of contact for a person with symptoms is that of their family doctor. A wide range of literature has considered the role of family doctors and other staff who work within primary health care in detecting dementia. This has arisen because of the increasing emphasis on early diagnosis and the belief that family doctors are in an ideal position to detect and diagnose dementia given their close relationships with their patients and their ability to monitor them over time (Koch & Iliffe, 2011, Koch & Iliffe, 2010a, Belmin, *et al.*, 2011).

Literature demonstrates expectations that family doctors should be involved in a range of activities associated with dementia. These include; screening, although the definition

of screening varies between studies and tools require further validation (Delepeleire, *et al.* 2008); to detect and assess at an early stage, (van den Dungen, *et al.* 2012) even though evidence suggests that this is particularly challenging for family physicians, (Mitchell, *et al.* 2011); to refer people with uncertain symptomatology to specialists (Belmin *et al.* 2012, Delepeleire *et al.* 2008); management, follow up and treatment, (Koch & Iliffe, 2010a, Belmin *et al.* 2012) and finally to document their assessment, diagnosis and management (Mitchell *et al.* 2011). However, literature highlights that there are low rates of detection in primary care, poor documentation, evidence of not being aware of impairment in patients, lack of diagnostic assessment and limited support at follow up (Belmin *et al.* 2012, Mitchell, *et al.* 2011).

A considerable body of evidence has identified a range of barriers to the family doctors involvement in the above activities in relation to early detection. These barriers include; an unwillingness to detect and diagnose dementia in their patients (Koch & Iliffe, 2010a; Mitchell, *et al.* 2011, Hanson, *et al.* 2008); nihilistic attitudes, believing that nothing can be done to help people with the condition (Hanson, *et al.* 2008, Martinez-Lage *et al.* 2010); a lack of education and skills concerning the detection, assessment, diagnosis and disclosure of a diagnosis of dementia (Koch & Iliffe, *et al.* 2010a, Martinez-Lage, *et al.* 2010, Belmin, *et al.* 2012) and delays in diagnosis due to patient factors such as stigma and delayed presentation, (Mitchell, *et al.* 2011, Koch & Iliffe, 2010a). Finally, family doctors also identify that the proportion of people who have dementia is low in their practice population, for example it is likely that they will only see one or two new people with dementia per year, and only have around twelve to fifteen people in a caseload of 2000 (Koch & Iliffe, 2010a). Many of the barriers raised here are also identified to be relevant to community based nurses working in primary care (Manthorpe, *et al.* 2003).

Research has subsequently attempted to address these barriers through a range of interventions. These can be subsumed into 4 main areas:

### **1. Educational Interventions**

A number of research studies over the last decade have attempted to address the knowledge and skills of family doctors, seeking to identify changes in detection rates and management of people living with dementia and their families. Recent systematic reviews of these studies have highlighted that in order for education to be effective, particular strategies are necessary. These involve facilitated education in practice based workshops which employ active learning, enabling the family doctors to identify their own learning needs. Furthermore, the availability of decision support software to be used in detection supports learning (Koch & Iliffe, 2011, Perry *et al.* 2010). However

these reviews also identify that these interventions may improve detection rates but they do not have an impact on management of people living with dementia on their caseloads (Mitchell, *et al.* 2011, Belmin, *et al.* 2012, Gibson & Anderson, 2012). Koch & Iliffe (2011) conclude that educational interventions are not effective on their own in improving practice.

## **2. Increasing access to specialists**

Literature suggests that increasing access to specialists improves detection and management of dementia (Koch & Iliffe, 2011, Belmin, 2012) and in a recent systematic review, Mitchell *et al.* (2011) conclude that family doctors should not be expected to make diagnoses alone. Where shared care exists, it has been identified that fewer false positive identification occurs (van den Dungen, *et al.* 2012) and furthermore that family doctors value shared care (Russ, Calvert & Morling, 2012). However it is evident that the availability of specialist support varies considerably across Europe, and in particular within rural areas, thus creative methods of enabling access to specialists needs to be addressed, including for example through telehealth videoconferencing (Morgan, Innes & Kisteniuk, 2011).

## **3. Case Management**

Case management methods of improving practice within primary care have primarily been implemented in the USA, with evidence of positive benefits (Belmin, *et al.* 2012, Vickery, *et al.* 2006, Gibson & Anderson, 2012, Mitchell, *et al.* 2012). Models of case management include the provision of a specialist geriatric nurse or social worker, who provided assessment; monitoring; care planning; management and co-ordinating care (Koch & Iliffe, 2010a). Such interventions were found to be beneficial in ensuring care responded to guidelines and increased referral on to other services (Koch & Iliffe, 2010a) and also resulted in higher levels of satisfaction from caregivers (Gibson & Anderson, 2012). Furthermore, they facilitated a multidisciplinary team approach (Belmin, *et al.* 2012). However it is also recognised that case management is likely to be a cost intensive strategy, which may be beyond the capacity of some European countries.

## **4. Development of guidelines including a 2 step approach to assessment**

Recently, guidelines have been developed to facilitate assessment processes in primary care (Perry, *et al.* 2010). These have been welcomed and viewed as a necessary step forward in enabling family doctors to work effectively (Koch & Iliffe, 2010a). In a recent systematic review, Mitchell *et al.* (2011), suggests that guidance on assessment should recommend a 2 step approach, involving an initial consultation based upon clinical

judgement followed by a second consultation in which cognitive testing is carried out. However, these authors also suggest that while this will improve diagnostic assessment, more accurate assessment measures are needed to ensure this is effective.

In summary, reviews of these interventions suggest that they are most likely to be effective when carried out in combination (Gibson & Anderson, 2012) however, Koch and Iliffe (2010a) indicate that “*careful thought ought to be given to the development of more efficient and innovative care provision and pathways that will be able to amalgamate [these] strategies*” (p108).

### **Targeted Screening**

A further issue for consideration when addressing the role of primary care is that of screening. It is suggested that targeted screening or opportunistic screening could be an appropriate strategy at this current time, given the significantly low rates of detection of dementia worldwide (Prince, *et al.* 2011b, Manthorpe, *et al.* 2011). Opportunistic screening refers to the identification of people who may have dementia within a defined population, for example a practice population of a family doctor, or within a hospital or care home population, involving utilising normally occurring opportunities for contact with the person to implement a screening process. Targeted screening refers to the identification and screening of specific groups of people who may be at risk, for example people with learning disabilities or those over the age of 85. As indicated in the section on population screening, people surveyed are not necessarily resistant to the idea of screening, on the assumption that treatment would be provided if a positive result were to be found (Hoslinger *et al.*, 2011).

Prince *et al.* (2011b) particularly emphasise the value of screening in low and middle income countries in order to improve detection rates, involving non specialists delivering assessment tools such as the brief, Community Screening Instrument for Dementia (Prince *et al.* 2011a) or the WHODAS II (Sousa, *et al.* 2010). These authors further suggest that these screening strategies may be appropriate within higher income countries as well.

However, one of the particular challenges that is emphasised in earlier literature is the presence of appropriate screening tools, and particularly ones which have proven sensitivity and specificity, while being brief and applicable to a diverse population (Mitchell & Malladi, 2010a & b). These authors have identified that a number of appropriate and brief measures are available; however it is evident that these are applicable to an English language speaking population and have rarely been validated for use in low and middle income countries with different cultures and languages or

with migrant communities (Prince *et al.* 2009, Neilson, *et al.* 2011). Thus further work is required to adapt them to the diverse countries within Europe.

While it appears that these methods of screening are recommended within health care settings, the barriers to the delivery of earlier and timely detection in primary care identified above and the need to ensure adequate intervention following detection and diagnosis are equally as important when considering opportunistic or targeted screening. A recent study in the United States (ROAM, Boise, *et al.* 2010) highlighted barriers including reluctance to follow up on a positive dementia screen, and the belief that a diagnosis of dementia is not beneficial. Further issues included the lack of time available to carry out assessment. Consequently, in order for targeted or opportunistic screening to be successful, education, care management and shared care arrangements would need to be addressed.

### ***Specialist Services for Early Diagnosis***

Across Europe, a number of different disciplines are involved in specialist assessment and diagnosis of dementia, including neurologists, psychiatrists, geriatricians, clinical and neuropsychologists, nurses, and occupational therapists (Boustani, *et al.* 2011, Willis, *et al.* 2009, Page *et al.* 2012). The most common specialist doctors to carry out diagnostic assessments in Europe are neurologists (Robinson, *et al.* 2010). These authors indicate that specialist doctors carry out a diagnosis of Alzheimer's disease alone in 65% of cases. People are referred by family doctors in order to commence medication; for differential diagnosis and to gain a second opinion. In recent years the development of memory services has occurred, for a number of reasons, including the increased demand for assessment and care (Lindesay, *et al.* 2002); the numbers of people who never receive a diagnosis (Page, *et al.* 2012) and more recently in response to drivers from National Dementia Strategies (Department of Health, 2009, 3<sup>rd</sup> French Alzheimer Plan, 2008, Ramakers & Verhey, 2011).

The experience of service received from specialist services for people living with dementia and their families in literature has been variable, with some people being subject to a 'revolving door syndrome' (Pratt, Clare & Kirchner, 2006) in which discharge occurred after diagnosis, and further contact with health and social care only occurred again when their situation worsened and frequently became a crisis. Furthermore these authors highlight that many people with early dementia and their families had significant needs, but that these needs remained largely unmet. This was even more likely for minority groups including migrants (Neilson, *et al.* 2011a, b. c.). However other literature has highlighted that memory assessment services have been valued by some, with specific comments including the approach of staff and short delay

from referral to assessment (Montgomery & Coles, 2003, van Hout, *et al.* 2001). In response to this variability, quality standards have been developed to enable services to be assessed and to implement improvements where that is found to be necessary (Doncaster, McGeorge & Orrell, 2011). These authors recommend that a nationally agreed set of quality standards is needed to improve the quality of services, and a revised set of standards has recently been developed, (Doncaster, McGeorge, & Orrell, 2011).

Memory assessment services are generally involved in seeing people with mild to moderate dementia, providing comprehensive multi-disciplinary assessment, diagnosis and prescription of medication (Willis, *et al.* 2009, Delepeleire, *et al.* 2006). However, the models of provision have needed to develop in recent years in order to be responsive to different needs of the population they serve and the localities in which they operate (Ramakers & Verhey, 2011). Literature highlights the specific ways in which services have developed to respond to the challenging nature of the work, including the numbers of people with symptoms being referred, rurality, links with primary care and the delivery of interventions as well as assessment.

### ***Core Generic team working/ extended roles of other professionals***

While traditionally it can be seen that doctors carry out assessments leading to diagnosis, the pressure numbers of people being referred into services has required alternative models to be developed. The Croyden Memory Service Model describes generic team working in which all team members irrespective of clinical background; carry out a core initial assessment. Following this a diagnosis is made and a management plan is formulated by the whole team (Banerjee *et al.* 2007). A further study highlights that other professionals in this case Nurses, Social Workers and Occupational Therapists, with appropriate training, can assume greater responsibility for assessment and diagnostic processes, thus allowing a greater throughput of clients through memory assessment (Page, *et al.* 2012). Finally, Delepeleire *et al.* (2006) indicates that multidisciplinary evaluation is necessary because of the complexities of achieving a diagnosis at an early stage.

### ***Location of service***

Perry *et al.* (2008) evaluated the effectiveness of an in home programme for people living at home, in achieving detection of dementia. This evaluation found considerable under recognition of dementia in primary care, and that furthermore, the programme resulted in a statistically significant increase in detection. Gibson *et al.* (2007) also carried out a comparative qualitative evaluation of a service provided in the person's



home with one that was clinic based. This evaluation highlighted that while satisfaction with the clinic based service was high, participants particularly valued the benefits of being seen at home. Particular benefits included feeling more relaxed, an informal approach, and feeling that their identity was maintained and that access to the service was considerably easier. These authors highlight the importance of considering spatial and location based issues in the design of services, which may lead to greater levels of user-friendliness. However this was a small scale qualitative study, carried out in an urban area, it is not clear how transferrable such a service would be in a rural location with significant distances to travel between clients.

### ***Locating a service within primary care***

As was highlighted in the previous section on primary care, developing shared care is likely to improve family doctors ability to detect and respond appropriately to people with symptoms presenting at their surgery. One model of clinic that has been developed involves implementing an interdisciplinary memory clinic within primary care (Lee, *et al.* 2010). This model has also been developed elsewhere, although evaluation of this service is not yet available (Callahan, *et al.* 2011). Lee, *et al.* 2010, describe the purpose of the clinic as being to provide timely access to comprehensive assessment and care and to improve referring family doctors' knowledge of the management of dementia through collaborative care and practice –based mentorship. Evaluation found that the model allowed family doctors to become more knowledgeable and skilled in their work with people with dementia. This allowed for monitoring and early intervention where difficulties occurred, for example if a person was progressing from MCI to dementia. This is further supported by other recent studies (Greening, *et al.* 2009, Meeuwssen, *et al.* 2012).

### ***Providing memory assessment services in a rural location***

Rural areas experience particular challenges in providing memory assessment services including travel costs, limited resources; time to travel; stigma, difficulty in recruitment of staff involved in delivering services. A recent systematic review has considered the scientific literature on service provision in rural and remote settings (Morgan, *et al.* 2011). This review has highlighted some specific recommendations for the provision of remote and rural memory assessment services including the use of telecommunication technologies to deliver dementia specific training to staff and to overcome professional isolation. They also identify that tele-health videoconferencing can be effectively used to provide assessment and consultation leading to a diagnosis of dementia and that this was acceptable to those who were being assessed.

### ***Providing intervention as well as assessment***

Willis *et al.* (2009) describe the interventions provided by the Croyden Memory Service, to include systematic feedback of the diagnosis, individual and group psychotherapies, medication, management of behavioural and psychological symptoms of dementia, access to social services and benefit advice. In both the qualitative and quantitative evaluation of the service, benefits from providing interventions as well as assessment were found. These included improvements in quality of life, learning adaptive strategies, developing knowledge and addressing the emotional aspects of caring (Banerjee, *et al.* 2007, Willis, *et al.* 2009). Banerjee & Wittenberg, (2009) concluded that early diagnosis and intervention could delay negative outcomes in care.

### **Benefits of and Risks associated with Early and Timely Diagnosis**

An emerging body of literature has outlined the benefits of an earlier and timely diagnosis in dementia, with much of this literature arising from the risks and costs associated with either the absence of a diagnosis or a later diagnosis of dementia. These risks have included that the majority of people with a later diagnosis or an absence of a diagnosis of dementia but with significant impairment, and their family members are not in a position to benefit from the access to services and treatments that a diagnosis would provide. Accordingly, the risk of crisis and long term care placement are greatly increased (Prince *et al.* 2011b, Woods *et al.* 2003). The purported benefits and risks of an earlier and timely diagnosis of dementia are summarised here, however it is important to note that it is believed that some of the literature in this area represents expert or other opinion based literature rather than being evidence based and thus further research is required (Prince *et al.* 2011b).

### ***Benefits for the person with dementia and their family members, supporters and carers***

#### *The right to know and to make decisions based on that knowledge*

The principles of autonomy and rights to self determination are enshrined within human rights legislation and apply equally to people with dementia (Nuffield Council on Bioethics, 2009). This includes the right to choose whether to undergo an assessment and to know the results of that assessment. Addressing cognitive difficulties at an early stage maximises the capacity of the person to engage actively and autonomously in this process, before capacity is affected. Early discussions in the form of pre-assessment counselling can facilitate the opportunity to make an informed decision about engaging in assessment when the person is ready (Williams, 2004). Early and timely diagnosis can then create important opportunities for the person to make decisions about the support

and information they wish to receive. This support can include developing an understanding of their symptoms; making decisions about medical and psychosocial care, development of coping strategies; and making advance decisions concerning their future and their finances (Trigg, *et al.* 2007, Clare, *et al.* 2005, Milne & Peat, 2008, Derksen *et al.* 2006, Vernooij-Dassen *et al.* 2006). Furthermore, it creates opportunities to express and address experiences of loss and grief, adjust and develop ways of adapting to the changes occurring (Milne & Peat, 2008, Betts Adams & McClendon, 2006, Derksen *et al.* 2006, Vernooij-Dassen *et al.* 2006, Prince *et al.* 2011b).

#### *Increased quality of life*

Evidence suggests that early diagnosis and intervention can improve quality of life and well being for people living with dementia and their families and carers (Banerjee and Wittenberg, 2009, Mittleman, *et al.* 2008). This is supported by consultation on dementia strategies within Europe, Australia and the USA, (see for example the National Dementia Strategy for England, Department of Health 2009). However studies evaluating the impact of early intervention have not always included measures assessing quality of life or well being, thus further research is required.

#### *Access to treatment, intervention and services*

Early and timely diagnosis allows people with dementia to gain benefit from access to treatments, interventions and services which are suggested to improve quality of life, facilitate hope and the opportunity to live well with dementia. Furthermore there is evidence that early intervention can delay cognitive decline, maintain functional abilities and delay admission to institutional care (Prince *et al.* 2011b, Banerjee & Wittenberg, 2009, Gaugler, *et al.* 2005, Banerjee *et al.* 2003, Waldemar, *et al.* 2007a, Milne, 2010). Access to early and timely diagnosis followed by intervention is also seen to improve outcomes for family members and others involved in caregiving, and in particular have been demonstrated to delay time to placing the person with dementia into long term care, improve coping and reduce the risk of depression (Mittleman, *et al.* 2006, 2007). Early assessment may also enable identification of those whose early signs of cognitive changes are not due to dementia, thus facilitating access to earlier diagnosis and appropriate treatment for their condition (Mattsson, Brax and Zetterberg, 2010, Milne, 2010). Thus early diagnosis and early intervention have the potential to achieve significant benefits for the person and their family.

#### ***Benefits for the Health and Social Care Economy***

It is suggested that the costs of dementia are set to increase significantly over the next 20 to 30 years, in line with the increase in the numbers of people living with dementia

(Comas-Herrera *et al.* 2007). Investment in the development and broad implementation of early diagnosis and interventions including medical treatments could offset some of the increasing costs of dementia occurring in the longer term (Banerjee & Wittenberg, 2009, Getsios *et al.* 2012, Weimer & Sager, 2009). Some economic modelling suggests that even though early intervention has significant upfront costs, it has the potential to '*substantially reduce expenditure growth*' (Comas-Herrera *et al.* 2007: 1044) thus providing social and fiscal benefits (Weimer & Sager, 2009). These benefits are thought to be particularly true for interventions that improve functional ability in the person living with dementia and provide effective support and services for families involved in caregiving (Weimer & Sager, 2009, Banerjee and Wittenberg, 2009, Gaugler, *et al.* 2005). These examples of economic modelling are acknowledged to suffer from limitations, including that there is an absence of longer term randomised controlled trials to form the basis of this modelling and that they are based upon one country (UK) and thus are not immediately transferrable to other cultures and communities (Weimer & Sager, 2009, Banerjee and Wittenberg, 2009). However Banerjee & Wittenberg argue that given the inefficiencies of current systems, it is believed that a reduction in costs with the proposed developments in early intervention would be possible (2009). Thus early diagnosis and intervention is perceived to be advantageous from a cost and social perspective (Bamford, 2011).

### ***Risks for the person with dementia, their family members, supporters and carers***

#### *Attitudes towards dementia*

Considerable evidence of stigma exists towards dementia worldwide, and particularly so in low and middle income countries (Prince, *et al.*, 2011b, Prince *et al.* 2009, Moniz Cook & Manthorpe, 2009). Although, awareness campaigns within high income countries seek to challenge stigma and address the potential to live well with dementia, stigma still influences the willingness of some to seek assessment and diagnosis. Furthermore, attitudes towards dementia can have a significant impact following diagnosis, involving potential loss of relationships and networks and valued activities (Stokes, *et al.* 2012, Moniz Cook & Manthorpe, 2009). Some also suggest that an early diagnosis could generate feelings of hopelessness and despair, loss of self esteem and self stigmatization, and possibly extend the time of anticipatory loss (Mattsson, Brax & Zetterberg, 2010, Milne, 2010, Iliffe & Manthorpe, 2004). Attitudes towards dementia including stigma can be a particular challenge for migrant communities where understanding and concepts of dementia are not necessarily congruent with the host culture and as a consequence may negatively influence their willingness to seek

assessment and diagnosis (Prince *et al.* 2011a, Prince *et al.* 2011b, La Fontaine, *et al.* 2007, Nuffield Council on Bioethics, 2009).

### *Misdiagnosis*

Misdiagnosis is a risk in early dementia (Mitchell, *et al.* 2011, Brodaty, *et al.* 2006, Milne, 2010). As indicated earlier in this review, the ability to detect dementia at an early stage is a complex process involving a number of factors which may result in a lengthy and prolonged process of assessment. This is particularly true for people with complex presentations, such as people with intellectual disability. Evidence of difficulties in detecting early dementia within primary care coupled with less sensitive screening assessment measures that may inappropriately identify a person as having dementia are particularly concerning. Although this may present a small risk in well developed systems of care, where limited service provision exists, the risk of misdiagnosis could be higher and even one person being misdiagnosed can have serious consequences (Milne, 2010, Mitchell, *et al.*, 2011, Brodaty, *et al.* 2006).

### *Is an early diagnosis better than a later diagnosis?*

Mattsson, Brax and Zetterberg, (2010) highlight a particular ethical challenge associated with early diagnosis in relation to advance decisions. They indicate that conflicts may arise in making decisions at an early stage about one's future, when it is very difficult to know what one will want or need at a future time, particularly given the manner in which dementia affects personality and cognition. While they do not suggest that early diagnosis is inappropriate, they do highlight the risks associated with it, and suggest that it is important to consider what is involved for the person and their family when faced with delivering an assessment and early diagnosis.

### *Loss of Autonomy*

Finally, it is necessary to consider the possibility that the drive towards early diagnosis in the absence of a recognition of the right to choose when, where, at what pace and whether to undergo assessment could result in an outcome that is not at all beneficial for the person or their family (Milne, 2010, Iliffe & Manthorpe, 2004). While the evidence for early diagnosis is increasing, it is important to place the person's needs and their right to choose, at the centre of this process. Although less frequently occurring in research, a minority of people identify that they do not necessarily want assessment or want to know what is wrong following assessment, (Boustani, *et al.* 2006, Keating *et al.* 2005) and it is suggested that resistance to medical intervention may be for some, an attempt to maintain control and resist the stigma associated with such assessment rather than denial of dementia itself (Milne, 2010). It is therefore fundamental that

approaches to early and timely diagnosis involve a combination of perspectives from medicine and those of people who may have dementia and their families (Milne, 2010).

### ***Risks for the health and social care economy***

The challenges of early diagnosis involve in particular the costs of establishing appropriate and effective systems for early diagnosis and intervention, in the context of either an absence of provision or provision which is targeted at a later stage in the experience of dementia (Prince, *et al.* 2011b, Banerjee & Wittenberg, 2009, Weimer & Sager, 2009). Where service systems exist, provision for dementia can be divided between health and social care, with early dementia incurring health related costs and later dementia incurring more social care costs. Thus establishing systems for early diagnosis can be particularly challenging when the cost savings of such services are not likely to be realised for some years to come and may not be realised from the same budget. Thus investment in such services requires a willingness to 'spend to save' in the longer term and joined up budgets where such savings can be realised (Banerjee & Wittenberg, 2009).

### **Conclusions**

Much of the literature described in this review is grounded in countries with advanced health and social care systems, mainly in Northern and Eastern Europe (Hausner, *et al.* 2010). However, across Europe, considerable diversity exists in service provision for people living with dementia and their families, in regard to the delivery of assessment, diagnosis and interventions (Hausner, *et al.* 2010). Hausner *et al.* found that a number of psychosocial factors influence help seeking, diagnosis and the experience of living with dementia for the person and their family including; norms concerning family responsibility; the extent to which people were likely to live alone or with family; as well as availability of service provision (Hausner *et al.* 2010). Although there are limitations to this study, it highlights in particular that European countries will need to develop tailored responses to the needs of the population of people with dementia and their families in regard to early and timely diagnosis. Furthermore, the results of this body of literature cannot necessarily be applied wholesale to countries that do not have such well developed systems of care (Prince, *et al.* 2011b). Thus any recommendations developed for use across Europe will need to address the diversity of service provision and need.

Nevertheless, a number of clear conclusions can be drawn from this review of the literature concerning early and timely diagnosis. These are as follows:

1. Taking into account the issues raised above, at the present time, the focus of 'early' diagnosis should be on advancing the point of diagnosis to the earliest stage possible, which for many countries will be from a later (Time point 4) to an earlier and timely diagnosis (between time point 2 and 3), in which cognitive change and disability is already present (Prince *et al.* 2011b).
2. The person and their family/ significant others should be placed at the centre of this approach, recognising that living well with dementia involves a lengthy and complex process of psycho-social adjustment. The person and family centeredness of the process includes promoting choice and control over assessment, diagnosis and intervention in order to support this adjustment. Thus research evidence suggests that a number of steps, outlined in this review (49-50), should inform the development and delivery of early and timely assessment, diagnosis and intervention for people living with dementia and their families.
3. Stigma and fear concerning the impact of dementia upon self esteem and identity, and lack of knowledge about dementia contribute significantly to the willingness to seek assessment and diagnosis, and to living with dementia following diagnosis. Raising awareness alongside the development of services for assessment, diagnosis and intervention is essential to facilitate an increase in understanding and to challenge stigma. It would seem that this is a necessary precursor to achieving an increase in numbers of people diagnosed at an earlier and timely phase.
4. Recent publication of all cause criteria for diagnosis of dementia syndrome, and for diagnosis of subtypes incorporates advances in assessment, pathology and etiology of dementia, as well as addressing concerns about sensitivity and specificity. While some of these criteria require further validation and possible revision, they represent considerable advances in the processes required to diagnose dementia and are recommended for use in clinical practice.
5. Diagnostic assessment should involve a multi-disciplinary, rigorous and holistic process which is delivered in two stages. Firstly to achieve differential diagnosis, including the exclusion of other possible explanations for the symptom experience, and secondly to achieve diagnosis of subtype.
6. People experiencing dementia represent a heterogeneous group, where specific factors such as age of onset, pre-existing health difficulties, ethnicity and pre-existing intellectual disability can make diagnosis a complex and challenging process, requiring assessment by specialists and/ or development of specific and appropriate assessment processes related to that particular population.
7. Family doctors and their colleagues in primary care are in an ideal position to recognise symptoms, screen and refer on where appropriate. However, significant challenges are faced in detecting dementia at an early stage, with a high risk of false positives. Research indicates that a number of processes are required in combination to support family doctors and their colleagues in

detecting at an early stage, including shared care with specialists, guidelines in detection, education and case management.

8. Opportunistic or targeted screening by family doctors and their colleagues may be an appropriate strategy to detect dementia at an earlier and timely stage. However in addition to addressing the processes mentioned in 7 above, the context in which screening occurs also needs to be considered. Screening populations where limited or no service provision beyond detection exists and where stigma is significant may present considerable risks to the wellbeing of people with dementia and their families. Thus targeted or opportunistic screening is most likely to be effective and acceptable when awareness raising and service development has occurred.
9. The provision of specialist assessment, diagnostic and intervention services is a particular strategy adopted by some European countries in order to achieve earlier diagnosis and interventions. While early evidence suggests that this strategy can achieve positive outcomes, research also indicates that such services will need to be responsive to a diverse range of challenges. These include the increasing numbers of people with dementia and the availability of appropriately qualified staff to carry out this process; the rurality of many countries making alternative measures such as tele-health assessment necessary; the location of the service, including whether it is provided in primary care or in people's own homes and finally the provision of interventions following diagnosis. All of these factors will need to be taken into account in the delivery of specialist early and timely diagnosis of dementia.

#### **Section 4: Diagnosis at Time Point 4, Moderate to Later Diagnosis**

As indicated in the section of this report on early diagnosis, many people do not ever receive a diagnosis of dementia. Where a diagnosis does occur; it is frequently much later in the experience of dementia. Help seeking is often influenced by the considerable impact that changes in functioning, including behaviour and activities of daily living, have on the lives of the person with dementia and their family, and may arise from a crisis having been reached (Bamford, *et al.*, 2004, Carpenter & Dave, 2004, Prince, *et al.* 2011b). As a consequence, a number of risks are present in a later diagnosis of dementia, including poor outcomes such as depression; placement in institutional care and loss of the ability to plan for the future (Prince *et al.* 2011b, Iliffe & Manthorpe, 2004).

While an earlier and timely diagnosis of dementia is therefore recommended, it is also recognised that for many countries, the capacity to achieve a diagnosis at this stage is hindered by many factors, including stigma, awareness, nihilistic attitudes, availability of service provision and of professionals with knowledge and expertise in diagnosis (Prince, *et al.* 2011a, Prince, *et al.* 2011b, Vernooij-Dassen, *et al.* 2005, Hausner, *et al.* 2010,



Prince, *et al.* 2009). Thus diagnosis at the moderate to later stages of dementia continues to occur in many European countries.

However, very little literature exists that directly addresses a diagnosis of dementia at a later stage. The body of literature that does exist is primarily from the USA, UK and Northern Europe. Thus the focus of this review is by necessity on those factors which may complicate diagnosis and lead to presentation at a later point in the experience and the additional psychosocial factors influencing assessment. For the sake of brevity, the processes that are congruent with those identified in the section on early diagnosis will not be repeated here, but referred to under these sections. This review then considers who presents at a later stage, where they present, who is involved in diagnosis and the factors influencing assessment and diagnosis in this context. Finally, the benefits and risks associated with a later diagnosis will be explored.

### **Diagnostic Classification of Dementia Syndrome**

The diagnostic classification of dementia syndrome referred to in earlier and timely diagnosis is equally applicable to diagnosis at a later point in the experience of dementia. Although also referred to in the chapter on an earlier and timely diagnosis, two specific issues which may lead to a later diagnosis or which complicate the diagnostic process, particularly for people who are experiencing dementia at an older age are considered in more depth (Brumback-Peltz *et al.* 2011). These are addressed below.

#### ***Co-morbidities***

Dementia is at its most prevalent in later life and frequently co-exists with other health conditions, as chronic and long term conditions are more common in later life. Older people are at greater risk of having; multiple acute and chronic health conditions, including infections, strokes and delirium; sensory loss; functional disability and physical frailty; and co-existing mental health conditions such as depression (Draper, *et al.* 2011, Korczyn & Halperin, 2009, Rapp, *et al.* 2011, Brumback-Peltz *et al.* 2011). Such conditions make differential diagnosis of dementia particularly complex, for example depression in later life frequently presents with significant cognitive features including impaired memory, attention and concentration, which may improve with appropriate treatment (Rapp, *et al.* 2011). Furthermore, the presence of delirium also makes differential diagnosis challenging, particularly where the person has persistent symptoms or only partial recovery (Cole & McCusker, 2009). Where repeated episodes of delirium occur, this may indicate an increased risk of developing dementia (Davis, *et al.* 2012). The presence of co-morbid health conditions prior to the onset of dementia may result in early signs of dementia being missed, in primary care, during acute care

treatment for medical conditions or when living in a care home (Siddiqi *et al.* 2011, Ferretti *et al.* 2010, Mukadam & Sampson, 2011). Brumback-Peltz *et al.* (2011) identify steps for achieving an appropriate differential diagnosis in this context including the following:

- Rigorous attention to history taking particularly from informants
- Presenting assessment measures in size 90 font, and using appropriate amplifiers for hearing loss combined with multimodal presentation of questions
- Use of normative data relevant to the age group of the person under assessment
- Flexibility of delivery of assessments, including shortening visits and visiting more frequently to carry out neuropsychological testing

### ***Mixed Pathology***

Older People experiencing dementia also have a greater risk of mixed pathology, including the combination of a Vascular and Alzheimer's pathology or DLB and Alzheimer's pathology (Ballard, *et al.* 2011, Snowden, *et al.* 2011, Dubois, *et al.* 2010, Brumback-Peltz *et al.* 2011). Brodaty *et al.* 2011, also indicate that 'pure' AD pathologies become less common in later life. Furthermore, Brumback-Peltz, *et al.* (2011) identify that the relationship between cognitive decline and evidence of pathology is much less clear in the oldest old. Therefore, the presence of a mixed presentation combined with dementia having progressed to the moderate and later stages make the diagnosis of specific subtypes in later life challenging although not impossible. Brumback-Peltz *et al.* (2011) suggest that further research is required to develop our understanding of diagnosis of subtype at this stage.

### **Who presents when cognitive changes are occurring at a moderate to severe stage and what factors influence their contact with services?**

In the section on early diagnosis, it was identified that the majority of first contacts with services to explore assessment were made by family members (Chrisp, Tabberer & Thomas, 2012a, Manthorpe, *et al.* 2011, Leung, *et al.* 2010, Koppel & Dallos, 2007). It seems likely that as the cognitive impairment progresses, the numbers of persons experiencing cognitive difficulties who will seek help may further reduce, as a consequence of challenges with understanding, awareness and insight. Thus those presenting with concerns are more likely to be family members or other involved in the person's life. The factors influencing presentation to services for assessment mentioned in the section on early and timely diagnosis are equally as relevant to those presenting at a later stage. There are however, a number of factors which are particularly associated with delays in seeking help. These include:

- Living alone, particularly where the person is female; has lower awareness; is older and although has less significant cognitive impairment, is at greater risk because of functional difficulties with activities of daily living (Ferretti, *et al.* 2012, Lehmann *et al.* 2010);
- Those who live with adult children (Iliffe & Manthorpe, 2004);
- Living in a care home, particularly because regular monitoring of care home residents does not necessarily occur in European countries (Iliffe & Manthorpe, 2004, British Geriatrics Society, 2011, Shah *et al.* 2010);
- Co morbid health conditions and disabilities, as identified above;
- Lowered awareness of the possible explanations for cognitive difficulties (Elson, 2007) which may arise from factors such as stigma and levels of public awareness (Prince *et al.* 2011b, Wimo & Prince, 2010) and cultural understandings of dementia (Seabrooke & Milne, 2009, Tilki, *et al.* 2010);
- Experiencing dementia at a younger age, influenced by denial, refusal to seek help, misattribution of symptoms, lack of confirmation from social context, professionals inadequate help and faulty diagnoses (van Vliet, *et al.* 2011 p1393).

As can be seen from the factors outlined above, living circumstances, family understandings and awareness of dementia and age all influence delays in seeking help. As cognitive impairment increases it seems possible that in the family context, delays in acknowledging and responding to cognitive changes lessen the opportunity for this to be a negotiated process. This increases the likelihood that the person with symptoms will be a passive recipient of the process resulting in risks to well being (Manthorpe, *et al.* 2011). Furthermore, the pre-diagnostic phase is known to be stressful for all family members, including the person with symptoms, due to the changes occurring in behaviour and normal activities of living. Therefore, an increase in distress and relationship difficulties is a possible outcome of delays in help seeking and diagnosis. (Manthorpe, *et al.* 2011, Chrisp, *et al.* 2011, Chrisp, *et al.* 2012b, Roseness, Ulstein & Engedal, 2009, Moniz-Cook, *et al.* 2006, Keady & Nolan, 2003, Chrisp, *et al.* 2012b, Stokes, Combes & Stokes, 2012).

However, not all people live at home with family members or live alone in the community. For example in the United Kingdom, one third of older people with dementia (diagnosed or undiagnosed) reside in care homes (Knapp & Prince, 2007) and over 40% of people aged 70 and over admitted to acute hospitals have dementia (diagnosed or undiagnosed) (Alzheimer's Society, 2009). Thus the first stages of detection of cognitive difficulties may be initiated by a professional involved in that person's care rather than by family. The issues associated with these settings are addressed later in this chapter.

## **How can processes be responsive to the needs of people with dementia and their families?**

The process of assessment, diagnosis and intervention should follow those principles outlined in the section on early diagnosis. However, the process will necessarily be influenced by factors that are more likely to be complex at a later stage including the capacity to consent (Nuffield Council on Bioethics, 2009) (This is addressed in depth in the work package on ethics and dignity); and the needs of family members and the person with dementia. In particular, the risk of negative outcomes is greater when diagnosis occurs at a later point and where services and support to live well with dementia are either not available or have not been involved (Prince, *et al.* 2011b). It is suggested that at this stage, a care oriented diagnosis is particularly important (De Lepeleire, *et al.* 2006), that this should incorporate an assessment of factors that might indicate a risk of poor outcomes (Zarit, *et al.* 2010, Czaja *et al.* 2009, Marziali *et al.* 2010) and that it should involve an identification of needs and appropriate support to assist them in coming to terms with and managing the impact of dementia (Robinson, *et al.* 2012). Furthermore, Stokes, Combes & Stokes, (2012) suggest that there is a need for partnership working and shared care to ensure that families are effectively supported.

## **Who do people with symptoms and their families receive detection, assessment and diagnosis from at this stage, and what are the key challenges involved in delivering this?**

In addition to detection of dementia within primary care, as indicated above, a later diagnosis is also associated with detection in care homes and acute care settings (Parke, *et al.* 2011, Nazarko, 2009, Zimmer, *et al.* 2010, Mukadam & Sampson, 2011). Each of these is addressed separately.

### ***Family Doctors and Primary Care***

The involvement of family doctors and their colleagues in primary care, including nurses has been addressed in detail, in the chapter on an earlier and timely diagnosis of dementia. While the discussion in that chapter is equally relevant to a later diagnosis of dementia, two further issues are relevant. Firstly, evidence suggests that family doctors are more confident in the detection of dementia at a later stage, and that they are more likely to achieve a positive identification, with accuracy increasing to eight out of ten people with cognitive symptoms (Mitchell *et al.* 2011). It is suggested that detection at this stage is more successful because family doctors use pattern recognition, (illness scripts) rather than medical deductive reasoning, and as activities of daily living become more impaired, success in detection is more likely (van Hout, *et al.* 2002).

Secondly, as discussed in the section on co-morbidity, people presenting with dementia at a later stage are more likely to be in late old age and have other, significant health difficulties (Draper, *et al.* 2011, Korczyn & Halperin, 2009, Rapp, *et al.* 2011, Brumback-Peltz *et al.* 2011). Thus they are more likely to be consulting more regularly with their family doctor or their colleagues as a result of these health difficulties. However, while this increases the opportunities for detection of changes in cognitive function, this has not necessarily increased detection rates overall, for reasons discussed in the chapter on early diagnosis including stigma and nihilistic attitudes towards the treatment for dementia (Mitchell, *et al.* 2011).

Following diagnosis, at a later stage, the role of the family doctor and their colleagues becomes particularly important, in enabling; a care oriented assessment (De Lepeleire, *et al.* 2006); access to appropriate services and information for the person and for family members involved in caregiving (Villars, *et al.* 2010); and management and monitoring (Villars, *et al.* 2010). This ongoing monitoring is particularly important in light of the experiences of many family members; including care packages not being maintained leading to crises arising (Pratt, Clare & Kirchner, 2006, Manthorpe, *et al.* 2011, Stokes, Combes & Stokes, 2012); and management of co-morbidities that may further complicate the experience of dementia (Villars, *et al.* 2010).

### **Care Homes**

As indicated earlier, evidence suggests that a significant proportion of residents living in care homes will have dementia, although this may not have been diagnosed. For example, in the UK, the mean age of residents in care homes is 85.4 and 56.9% of all residents are over 85 and thus in the age group that has the highest risk of developing dementia syndrome (Shah, *et al.* 2010). Ferretti *et al.* (2010) suggest that dementia is present in 1 in 4 residents, but less than a third of people have a diagnosis, especially for those who are the oldest old.

The reasons for lack of detection include that; routine monitoring of health conditions in care homes is variable, for example, while the Netherlands has instigated such procedures, the UK has not (Shah, *et al.* 2010, Hoffman, *et al.* 2011); where health checks take place, there is a focus on acute medical problems, thus dementia is missed (Hoffman, *et al.* 2011) and that staff experience difficulties in identification and appropriate training to detect dementia does not necessarily occur (Hoffman, *et al.* 2011, De Lepeleire, *et al.* 2006).

In order to address this lack of detection, De Lepeleire *et al.* (2006) suggest that appropriate guidelines needs to be written with care home staff in mind. Furthermore,

it has been identified that with appropriate training and supervision, staff working in care home settings are able to detect dementia and differentiate between those who have dementia and those who have delirium, (Siddiqi, *et al.* 2011, Zimmerman *et al.* 2010). It has also been identified that factors that need to be addressed in training include delivering a person centred philosophy, understanding behaviours of concern, communication, the multi-disciplinary team and knowledge of dementia (Beer *et al.* 2009). Furthermore these authors identify that small group training which is flexible; individualised; practical and case based was most likely to be successful (Beer, *et al.* 2009). Finally, the identification of leadership roles in dementia care that support knowledge development and practice have been found to be beneficial in improving practice with people with dementia as well as other conditions such as delirium in care settings (Siddiqi *et al.* 2011, Waugh, *et al.* 2011).

### ***Acute Hospital Provision***

As with care homes, there are significant numbers of people with dementia, receiving care for acute conditions, in hospital, intermediate care settings, accident and emergency departments and outpatient care, many of whom have not received a diagnosis of dementia (Parke, *et al.* 2011, Ferretti, *et al.* 2011, Alzheimer's Society, 2009). It is suggested that the 'oldest old' are most at risk of under-diagnosis, possibly due to the complications associated with co-morbidities highlighted earlier. People with dementia who are admitted experience a range of conditions giving rise to a health crisis, including fracture, delirium, constipation, head injury and infections (Draper, *et al.* 2011). It also suggested that people with a vascular pathology may also be more prevalent in acute care possibly due to the higher cardiovascular pathology (Mukadam & Sampson, 2011). Mukadam & Sampson further identified that having dementia and being admitted to an acute care setting was associated with being older, having poorer nutrition and functional ability and an increased risk of delirium. This leads to worse outcomes, increasing the length of hospital stay, functional decline and discharge to nursing home or institutional care (p 349).

A number of factors are identified as being responsible for the poor rates of detection; attitudes and beliefs about normal ageing; insufficient training of staff; difficulties in the environment causing challenges in implementing screening; absence of protocols for screening and detection; time constraints & poor adherence to dementia guidelines where these exist (Ferretti, *et al.* 2010, Mukadam, *et al.* 2011; Chodosh & Chodosh, 2007, Cowdell, 2010).

In order to detect and support people living with dementia more effectively it is suggested that these factors can be addressed through a combination of;

implementation of a person centred philosophy of care; appropriate training and leadership, including more specialised training for those who do not work in wards specifically for older people; the development of protocols or guidelines; a shared care model with specialist liaison services; development of brief assessment tools that have high sensitivity and specificity; addressing environmental design and the use of family members to act as key informants and support the care needs of the person with dementia (Park *et al.* 2004, De Lepeleire, *et al.* 2006, Draper *et al.* 2011, Clionsky & Clionsky, 2010, Waugh, *et al.* 2011, Parke, *et al.* 2011, Gandesha, *et al.* 2012; Leung & Todd, 2010).

## **Benefits of and Risks associated with Diagnosis at a Moderate to Severe Stage**

### ***Benefits for the person with dementia and their family members, supporters and carers***

The benefits of a later diagnosis, as reported in the section on early diagnosis are largely grounded in expert opinion, and inevitably reflect the risks associated with an earlier diagnosis. As attitudes towards dementia remain a particular challenge, it is perceived that a later diagnosis of dementia can enable some to maintain self esteem and resist the 'spoiled identity' associated with a diagnosis of dementia (Milne, 2010, Iliffe & Manthorpe, 2004, Moniz-Cook and Manthorpe, 2009) Furthermore, lessening the time with a diagnosis avoids labelling a family member as a carer prematurely (Iliffe & Manthorpe, 2004). As indicated in the chapter on an earlier diagnosis, adjustment to the experience of dementia is a psychosocial process, and a later diagnosis may allow more time for some to adjust to and seek support when they are ready to do so. Finally, a later diagnosis can involve less pressure to make future plans and therefore remain in control of personal affairs and finances for as long as possible, although clearly delaying help seeking risks a loss of capacity before decisions are made (Iliffe & Manthorpe, 2004)

### ***Benefits for the Health and Social Care Economy***

The benefits of a later diagnosis to the health and social care economy are limited to the avoidance of the costs associated with false positive identification (Iliffe & Manthorpe, 2004, Milne, 2010) and the increasing short term costs of earlier diagnosis. However, this is perceived to be a false economy, as although early intervention has significant upfront costs it has the potential to reduce expenditure in the longer term (Banerjee & Wittenberg, 2009, Getsios, *et al.* 2012, Prince, *et al.* 2011b, Prince, *et al.* 2010).

### ***Risks***

While the evidence associated with benefits of a later diagnosis largely represents expert opinion, the evidence concerning the risks of a later diagnosis is clearly outlined in literature discussing the reasons for an earlier diagnosis.

### ***Risks for the person with dementia, their family members, supporters and carers***

#### *The right to know and make decisions based on that knowledge*

Delaying the point at which the diagnosis is made risks a loss of the opportunity for personal decision making. This includes decisions about whether to undergo assessment and to maximise opportunities for planning for the future, as capacity is increasingly impaired as dementia progresses (Nuffield Council on Bioethics, 2009).

#### *Loss and adaptation*

Alongside the loss of opportunities for personal decision making, the psychosocial process of adjustment can also be delayed. Many people with dementia and their families are identified as wishing to know the diagnosis and in particular, having the opportunity to adjust and live well with dementia (Trigg, *et al.* 2007, Clare, *et al.* 2005, Milne & Peat, 2008, Derksen *et al.* 2006, Vernooij-Dassen *et al.* 2006). A later diagnosis risks that this adjustment is less possible to achieve. For example, relationships are important in enabling people living with dementia and their families to live well (Ablitt, *et al.* 2009). A later diagnosis of dementia with associated loss of capacity, communication and collaboration risks that this process is less likely to be achieved together resulting in experiences of isolation and loss (Stokes, Coombes & Stokes, 2012, Manthorpe *et al.* 2011).

#### *Access to and benefit from interventions*

The risk of a later diagnosis of dementia is that the person and their family members are less able to benefit from the psycho-social interventions, services and treatments that an earlier diagnosis would provide. Accordingly, the risk of poor outcomes, including crisis, depression and long term care placement are greatly increased (Prince *et al.* 2011b, Banerjee & Wittenberg, 2009, Woods *et al.* 2003). While services might be provided to support the person and their family at this stage, this may be too late to effect an intervention which delays admission to a care home, or to prevent poor outcomes for family members involved in caregiving, including physical and mental ill health, thus resulting in significant losses to all parties involved (Audit Commission, 2002, Stokes, Combes & Stokes, 2012, Banerjee & Wittenberg, 2009).

### ***Risks for the Health and Social Care Economy***



Evidence suggests that delays in treatment such as ACHE inhibitors; interventions such as effective strategies to enable behaviour to be understood and responded to, and services such as home based care, result in a substantial risk of increased costs in the longer term, for example in the use of long term care (Getsios, *et al.* 2012, Kronborg Andersen, *et al.* 2003, Luppá, *et al.* 2010, Lyketsos & Miller, 2012) Given the significant rise in numbers of people living with dementia worldwide, Prince *et al.* (2011b) indicate that an earlier diagnosis is an economic imperative to save health and social care costs as well as improving the lives of people living with dementia and their families.

## **Conclusions**

Many of the conclusions arising from the section on early and timely diagnosis are relevant to this section. Thus the following recommendations address those areas not covered in that chapter. Furthermore, given that the majority of studies were carried out in countries with high levels of care home provision and acute hospital care, as well as other systems, the results cannot be applied wholesale to those countries without such systems in evidence.

- A later diagnosis needs to follow the processes described for an earlier and timely diagnosis, however, these processes should take into account the factors that have influenced later help seeking and that may complicate differential diagnosis, thus adaptations to the process may be necessary to achieve a rigorous assessment while responding to the needs of the person and their family;
- A care oriented diagnostic process is particularly important where a later diagnosis has occurred. This needs to address the multiple factors which may have prevented help seeking at an earlier stage; the costs for the person and their family of this delay and the adjustment difficulties that may arise as a consequence. The final stage of the diagnostic process must include care management, involving addressing the treatment, interventions and services required to address the support needs of the person and their family;
- While it is more likely that family doctors and their colleagues are able to recognise and detect cognitive changes commensurate with a diagnosis of dementia at a later stage, factors such as co-morbidity may make detection complex. Thus the recommendations for facilitating detection, diagnosis and support made in an earlier diagnosis, are also relevant to diagnosis at a later stage;
- Professionals working in acute care settings and care home settings should also be supported to detect the presence of dementia in people presenting at their services. Such support would include the development of appropriate guidelines for detection and assessment combined with appropriate training; addressing leadership roles within these settings to address dementia and deliver a person

centred approach; partnership working with specialists to identify, diagnose and support people living with dementia and their families and finally the implementation of assessment processes that facilitate appropriate detection.

## **Section 5: Summary of Progress on Early Diagnosis France**

### **Alzheimer's Disease: Performance and quality of diagnosis in France 2012**

#### ***Background***

Alzheimer's disease and related disorders progress inexorably as people age: over 85 years old, one in every four women and one in every five men suffer from them. Faced with this major scientific, medical and social challenge, a commission chaired by Pr MENARD with 10 members, 8 working groups, 100 people, during 3 months provided a final report to the President on November 8<sup>th</sup>, 2007.

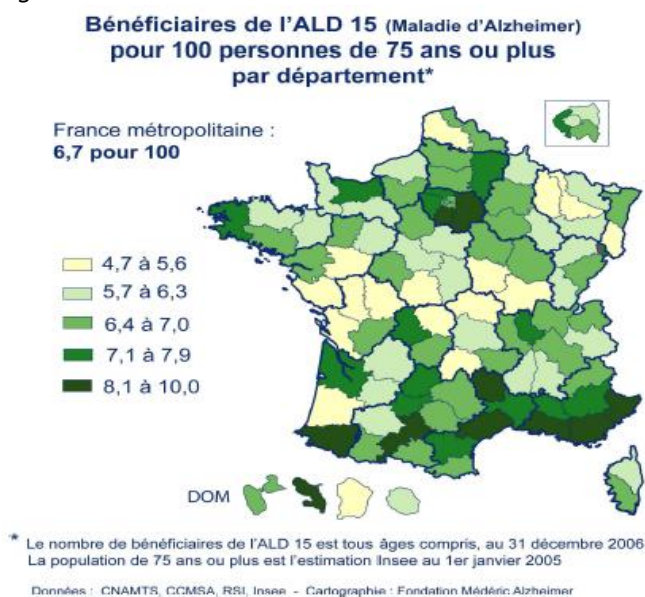
The President of the French Republic launched the "Alzheimer plan 2008-2012".on the 1<sup>st</sup> February 2008. Centred on the person with the disease and his or her family helpers, the plan aims at unprecedentedly developing research, facilitating a timely diagnosis and taking better care of the person and his or her helpers.

The main challenges of the plan were based on a financial effort over 5 years, with 200 Million Euros for research; 200 Million Euros for medical care; 1,2 billion Euros for medico-social support and a new governance based on transparency with direct reporting to the President of the French Republic every 6 months.

#### ***Context in 2008: major needs of the population***

The figures given on December 31st, 2006, regarding the number of people declared to the national health insurance system are shown on the following map:

Figure 3: Alzheimer situation in France



## French Alzheimer plan 2008 – 2012

44 measures and 11 objectives in order to fight Alzheimer's disease and related disorders are developed in the plan. In this context, improving access to diagnosis and care pathways is one of the major objectives. 5 measures address the question of diagnosis improvements.

### ***Measure n°8: Preparing and implementing a system for giving the diagnosis and providing counselling***

Given the specific characteristics of this disease, which calls for long-term social care beyond the medical treatment itself, the diagnosis must be given as part of a package of information for the patient and the family, not only about the disease itself but also about how the treatment plan will work and the possibility of social support. This information about the disease involves mobilizing all healthcare professionals.

The process includes a first stage: giving the diagnosis which should take place during a specialist memory consultation, whether this is with an independent neurologist or in a public or private hospital, and a second stage: confirmation of the diagnosis, explanation and support during consultations with the primary-care doctor.

In 2012 The French National Health Authority published good practices for giving the diagnosis and providing counselling and defined the role of each partner involved with the person with dementia: carer, primary-care doctor, independent neurologist, hospital team, patients' associations, medico-social partners etc.

[http://www.has-sante.fr/portail/jcms/c\\_1244873/maladie-d-alzheimer-et-maladies-apparentees-dispositif-d-annonce-du-diagnostic-et-d-accompagnement?xtmc=&xtr=2](http://www.has-sante.fr/portail/jcms/c_1244873/maladie-d-alzheimer-et-maladies-apparentees-dispositif-d-annonce-du-diagnostic-et-d-accompagnement?xtmc=&xtr=2).

***Measure S3: Specific consultation by Family Doctor for person with Alzheimer's and helpers at home***

In order to provide a timely diagnosis and more generally to offer people with dementia an integrated care pathway, participation of family doctors is important. Thus a visit at home with the carer has been created by the new medical convention of July 2011. It enables the family doctor to examine the person with dementia in his or her usual environment. The family doctor can assess remaining abilities, answer questions, reassess pharmaceutical treatments particularly anti-psychotics, assess the carer's health, and deal with other diseases. A higher payment for this visit is provided than would be given on an average home visit.

***Measure n°11: Creating memory units in areas that are not covered / Measure n°13: Reinforcing the very active memory units***

Memory units offer specialized medical consultations for persons suffering from memory or behavioural disorders. These units are part of general hospitals and have 6 major aims:

1. Expertise in the diagnosis of Alzheimer's disease or relative disorders
2. To inform the patient about his/her diagnosis with a disclosure process (tailor-made for the patient, taking into account his/her ability to assimilate information)
3. To talk clearly and concisely about the results of the assessment and the diagnosis made
4. To assess his level of comprehension and answer his questions review information already known by the patient such as the reason for this meeting
5. To inform and discuss with the GP
6. To manage Alzheimer's disease with local and social partners

Staffing in these memory units include at least a doctor (geriatrician, neurologist, and psychiatrist) and a psychologist trained in cognitive assessment. Since 2011, independent neurologists can also be recognized as memory units.

The “plan Alzheimer 2008 - 2012” created memory units in areas not covered and organized a national network of memory units (Cf. table below).

***Measure n°12: Creating "memory resource and research centres" in areas that are not covered***

Memory resource and research centres are expert centres in university hospitals. They carry out clinical research and training activities; they lead and organize the regional and/or interregional provision in partnership with memory units. Finally, they deal with the ethical questions raised by Alzheimer's disease. Each region should have at least one CMRR, which is a specialist centre providing diagnosis in the most complex cases and for the earliest forms. Three additional CMRRs (Auvergne, Corsica, Limousin) have been created to reach the territorial coverage objective.

Each Memory resource and research centre has five major roles:

1. Memory Clinic for out-patients referred to the centre by family doctors or medical specialists (Neurologists, Geriatricians, Psychiatrists)
2. Organization of the memory clinic network for the region
3. Teaching and training programs
4. Clinical research
5. Ethics

***Measure n°19: Identifying a national reference centre for young Alzheimer's patients***

People with dementia who are younger than 60 years (5,000 of them being identified by health insurance, of whom 2,000 are new cases each year) are faced with specific problems of delayed diagnosis or even misdiagnosis, socio-professional impact or care. The centre for young people with dementia ( <http://www.centre-alzheimer-jeunes.fr> ) established in February 2009 provides local medical and medico-social contact points throughout France to answer the specific questions asked by these patients. Its missions are:

- Developing knowledge, particularly in epidemiology and the social sciences;

- Reinforcing research, as the disease in young subjects constitutes an observation and analysis model enabling its genetic and physiopathological mechanisms to be better identified and innovative therapeutic methods to be imagined;
- Producing and distributing standards for good practice and shared tools to guarantee quality of care and to coordinate treatment across the whole territory.

This centre has become the regional, national and international reference point among both the professionals and the public. In 2011, over 2,700 young people with difficulties (+ 10% compared to 2010) were referred to the centre. More than one third of them were diagnosed with Alzheimer's disease or a related disease.

In September 2010:

- Number of young patients followed by national centre: 10 000
- Number of patients in epidemiological cohort of young patients: 207

*Table 9: Summary of situation in France*

|   | T0<br>31/12/2007                         | T4<br>31/12/2011  |
|---|--|---|
| Number of CMRR  | 25                                       | 28  |
| Number patients (in a year) CMRR                                      | 39 551                                   | 51 100  |
| Number of memory units  | 378                                      | 469   |
| Number of cognitive assessment by independent neurologist (in a year) | 29 856                                   | 39 000  |
| Doctors in memory units (fulltime equivalent)                         | Neurologists : 53<br>Geriatricians : 152 | Neurologists : 75<br>Geriatricians : 149<br>Psychiatrics 18<br>Other 22 |
| Number of patients (in a year) memory units                           | 111 251                                  | 132 873   |
| Average MMS   | CM : 18.8<br>CMRR ; 19.6                 |   |

***Measure n°34: Setting up epidemiological surveillance and follow up***

In France, one of the aims of the current national Alzheimer's disease plan is to collect data from all memory centres (memory units, memory resource and research centres, independent neurologists) throughout the country. Each participating centre is required to transmit information on patients to the French National Alzheimer data Bank (BNA). This involves completing a computer file containing 31 variables corresponding to a limited data set on AD (CIMA: Corpus Minimum d'Information Alzheimer).

In 2010, the BNA received data from 320 memory centres relating to 199,113 consultations involving 118,776 patients. An analysis of the data shows that the initial MMSE (Mini Mental State Examination) mean score for patients in France was 16.8 points for Alzheimer's disease, 25.7 points for mild cognitive impairment, and 18.8 points for 'related disorders related disorders. The BNA will provide longitudinal data that can be used to assess the needs of individual local health areas and size specialized care provision in each regional health scheme. By contributing to the BNA, the memory centres enhance their clinical activity and help to advance knowledge in epidemiology and medical research in the important field of Alzheimer's disease and related dementias. Since the implementation of the first Alzheimer Plan in France in 2001, the organization of testing and follow up for AD has been based on a nationwide network comprising 400 'memory units' (CMs: Consultations Mémoire) and 27 'memory resource and research centres' (CMRRs: Centres mémoire de ressources et de recherche).

The computer application "Calliope" is made available to centres for data entry, though they can opt for any one of a number of alternatives (Rapid, Onyx, 4D Nord, Alpha, etc.). Every time a patient visits a centre, the physician completes a patient file specifically designed for Alzheimer's disease and related diseases, which can be filled in online using a fully web-based application (i.e. physicians can enter the data online via a web browser without needing to have the application installed on their computer). Once the data has been entered, the application extracts the required minimum data set and transmits it to the BNA (see Figure 1).

A key point in the development of the system is that, since 20 May 2010, all the participating centres have been provided with the necessary online tools. Each centre now has its own access code enabling it to query the national database at any time and also access its own consolidated and anonymised data. Anonymisation has been done under the conditions of the Commission Nationale de l'Informatique et des libertés (CNIL) which is responsible in France for data protection and data use with respect to the human identity, the human rights, privacy and liberties.

On September 2012, 404 centres submitted at least one minimum data set (CIMA) to the BNA, 690 000 CIMA have been submitted for 300 000 patients.

Table 10: The French National Alzheimer Information System

| French national Alzheimer Information System   |                                    |
|--|------------------------------------|
| Major characteristics:   |                                    |
| <ul style="list-style-type: none"><li>• Decision to develop the system (Measure 34 of the French National Alzheimer Plan): December 2008</li><li>• First information sent to the BNA: October 2009</li></ul> |                                    |
| More than 100 memory centre sending information to the BNA: October 2009   |                                    |
| <ul style="list-style-type: none"><li>• Number of centre sending today (September 2012) to the BNA:</li><li>• Number of patient in the BNA* :</li><li>• Number of CIMA** in the BNA :</li></ul>              | <p>404<br/>295 241<br/>674 512</p> |
| <small>* National Alzheimer data bank (BNA)</small>  |                                    |
| <small>** The Alzheimer limited data set or CIMA (Corpus d'Information Minimum Alzheimer)</small>  |                                    |

### ***Accompany the diagnosis***

#### *Long term disease coverage*

Alzheimer disease belongs to the list of 30 long term diseases which benefit of (i) specific coverage for health care services and products and (ii) specific guidelines to set up ideal clinical pathways for optimal management.

ALD guidelines for practitioners, the lists of medical and paramedical services and products (LPS) and the ALD information booklets have been currently updated according to clinical guidelines on diagnosis and its disclosure.

[http://www.has-sante.fr/portail/jcms/c\\_1148883/maladie-dalzheimer-et-maladies-apparentees-diagnostic-et-prise-en-charge](http://www.has-sante.fr/portail/jcms/c_1148883/maladie-dalzheimer-et-maladies-apparentees-diagnostic-et-prise-en-charge)

ALD guidelines for practitioners describe ideal clinical pathways for optimal management. LSP is the list of medical and paramedical services and products which are involved. ALD information booklets are dedicated to set up dialogue with the patient on the essentials of the pathway.

#### *Long visit at home*

The long visit (VL), performed by the family doctor in the home of the person with dementia, is an opportunity to see the person in their usual living environment, and to verify the adequacy of support to meet their needs and their social network. It allows



the person and their family to participate actively in the decisions concerning the therapeutic and medical and social care needed.

This long visit was created within the framework of the Plan Alzheimer on 2008-2012 to improve the care at home of persons affected by an Alzheimer's disease or related disease.

It is registered in the agreement and came into effect on September 26th, 2011 between the family doctors and the CNAMTS.

The nature of this visit should be adapted according to the stage of the disease. It is not intended to replace that of a usual follow-up. Naturally, the visit can only take place if the diagnosis has been disclosed to the person and to their circle of acquaintances. This document proposes concrete questions and paths for its progress

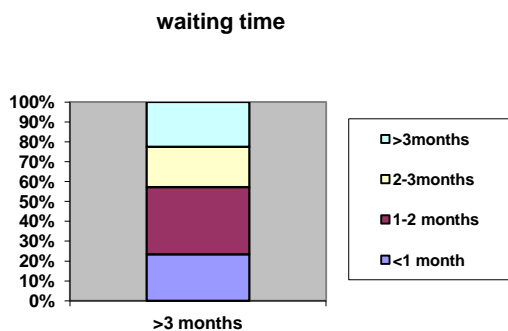
<http://www.inpes.sante.fr/CFESBases/catalogue/pdf/1401.pdf>

### **External assessment**

MEDERIC Alzheimer Foundation, a non-governmental organization realized a national survey in 2011, among 13 800 services supporting persons suffering from Alzheimer and their caregivers, including 511 memory units ([LA LETTRE DE L'OBSERVATOIRE DES DISPOSITIFS DE PRISE EN CHARGE ET D'ACCOMPAGNEMENT DE LA MALADIE D'ALZHEIMERN°24 - Juin 2012 - État des lieux 2011 des dispositifs d'accompagnement de la maladie d'Alzheimer](#) <http://www.fondation-mederic-alzheimer.org/Nos-Travaux/La-Lettre-de-l-Observatoire>)

The average waiting time for the first appointment in a memory unit is 52 days (62 days for memory resource and research centres in university hospitals).

*Figure 4: Average waiting time for first appointment*



In France, the average ratio of number of memory unit per 100 000 citizens over 75 is 9. In other words, this offers a consultation for 11000 elderly persons. Regarding the staff in memory units:

- 100% of memory units have a doctor in their team: 90% have a geriatrician, 20% a neurologist and a few psychiatrist)
- 97% have either a neurophysiologist or a psychologist
- 59% of the memory units offer supplementary services such as training or social activities for caregivers

## **Conclusion**

The general population study conducted at the plan's beginning showed that 91% of respondents would like their diagnosis to be disclosed to them if they had symptoms.

<http://www.plan-alzheimer.gouv.fr/measure-no37.html>

With the help of the Plan, the French territory is covered so that people with dementia get easy access within a reasonable time to a timely diagnosis. 469 hospital memory clinics are available with a total of 500 access points. Throughout France, access to a consultation by a specialist in hospital or in ambulatory setting is quickly available nearby. And the waiting time (measured in hospital memory clinics in October 2009) is reasonable: 51 days on average, 4 out of 5 giving an appointment in less than three months.

A diagnosis network is being structured around the 28 research and resources memory clinics with since 2011 new specifications for memory clinics and a label for memory clinics in ambulatory setting. Nevertheless too many people with dementia do not get a diagnosis or get it late.

In order to provide a timely diagnosis and more generally to offer people with dementia an integrated care pathway, participation of family doctors is important. Thus a visit at home with the carer has been created by the new medical convention of July 2011. It enables the family doctor to examine the person with dementia in his or her usual environment. The family doctor can assess remaining abilities, answer questions, reassess pharmaceutical treatments particularly anti-psychotics, assess the carer's health, and deal with other diseases. Practice guidelines for the diagnosis and treatment of dementia, the disclosure of diagnosis and the provision of support were published in November 2009 and December 2011. Recommendations in order to provide support at

home after the diagnosis and to define the relationship between doctor and MAIA are being developed.

People with dementia who are younger than 60 years (5,000 of them being identified by health insurance, 2,000 new ones each year) are faced with specific problems of delayed diagnosis or even misdiagnosis, socioprofessional impact or care. The centre for young people with dementia (<http://www.centre-alzheimer-jeunes.fr>) established in February 2009 provides local medical and medico-social contact points throughout France to answer the specific questions asked by these patients. This centre has become the regional, national and international reference point among both the professionals and the public. In 2011, over 2,700 young people with difficulties (+ 10% compared to 2010) were referred to the centre. More than one third of them were diagnosed with Alzheimer's disease or a related disease.

## **Recommendations**

To improve quality of diagnosis and timely diagnosis:

- There is a need to interest family doctors by offering training or possibility of a long and specific consultation. The initial identification of likely cases of dementia is an important function of primary care.
- 2 levels for memory centres : formal diagnosis should be done by specialists:
  1. A expert centre in university hospital, one per land for out-patients referred to the Center by General Practitioners or medical specialists (Neurologists, Geriatricians, Psychiatrists), This centre has to organize the memory clinic network for the region, Teaching and training programs, Clinical research and Ethics
  2. Memory units in general hospital or independent neurologists (or other specialists)
- Need for training in the basic medical, nursing and therapy curricula regarding diagnostic and needs-based assessment.
- Databank for public health survey/monitoring including patient diagnosis and outcomes
- Create a national reference centre for young Alzheimer's patients

A national databank is important for Public health and epidemiology:

- To have information about global demographic and clinical characteristics for all the patients consulting within the public national Memory centre network;
- To analyse these characteristics from year to year;

- To understand the differences between Alzheimer’s Disease and related disorders for example on loss of autonomy.

This databank is also important to improve the care system organization: to understand the population differences according the regional / geographical characteristics, to understand the population differences according to the type of centre (University research Memory centre, local Memory centre, private specialist), to provide an homogenous report of the clinical activity of each centre (monthly or annual basis), to provide information concerning the relation between patients demographic/clinical characteristics and pharmacological/non pharmacological prescription.

[Identifying a national reference centre for young people](#) with Alzheimer’s disease

Persons with YOD may still be working or may have recently left the workforce, they may have children still in the home or of university age, and they may not have the additional chronic conditions that the older population generally acquires. Furthermore, the information and support that is available to the older person with dementia is usually inappropriate. From a policy perspective, the young onset population requires specific consideration because eligibility for social /medical supports or old age pensions is frequently based on an attained age, and younger persons may not be able to access financial support.

A national reference centre for young Alzheimer’s patients need contact points with a referral doctor in each region.

## **Section 6: Summary of Progress on Early Diagnosis England**

### **National Dementia Strategy England**

A report published by Alzheimer’s Disease International in 2011 (Prince *et al.* 2011) suggested that up to 28 million of 36 million people living with dementia across the world had yet to receive a diagnosis, limiting their access to treatment, information and care. The report also identified lack of detection as a significant barrier to improving the lives of people with dementia, as well as their families and their carers, and suggested that the costs of early detection can be offset by projected future savings. The authors recommended that every country should have a national dementia strategy that promotes early diagnosis and intervention. The European Union has been quick to respond to this increasingly urgent agenda and to recognise the need to address the health, social and economic issues that dementia poses for society. In 2007 the European Commission (the EU’s executive body) funded the project “European Collaboration on Dementia – EuroCoDe”. This project, led by Alzheimer’s Europe,

included work to provide an overview of International, European and national guidelines on the diagnosis and treatment of dementia ([www.alzheimer-europe.org/EN/Research/European-Collaboration-on-Dementia](http://www.alzheimer-europe.org/EN/Research/European-Collaboration-on-Dementia)).

A number of Member States currently have a national dementia strategy (Alzheimer's Europe, 2013) including 4 strategies within the United Kingdom (covering England, Scotland, Wales and Northern Ireland). The purpose of this report is to assess the evidence for progress on early diagnosis against the strategy that has been developed in England which was launched in February 2009. The National Dementia Strategy for England was launched following an extensive consultation period, involving people living with dementia and their families, professionals working within the fields of health, social care and the third sector and other stakeholders. The outcome of this process of development, consultation and refinement was a strategy which had the goal of enabling people and their family carers to live well with dementia by addressing three main areas, summarised in the strategy as follows (Dept of Health, 2009: 21):

1. To encourage help-seeking and help-offering (referral for diagnosis) by changing public and professional attitudes, understanding and behaviour;
2. To make early diagnosis and treatment the rule rather than the exception; and achieve this by locating the responsibility for the diagnosis of mild and moderate dementia in a specifically commissioned part of the system that can, first, make the diagnoses well, second, break those diagnoses sensitively and well to those affected, and third, provide individuals with immediate treatment, care and peer and professional support as needed; and
3. To enable people with dementia and their carers to live well with dementia by the provision of good-quality care for all with dementia from diagnosis to the end of life, in the community, in hospitals and in care homes.

Seventeen objectives were identified under these 3 priority areas, of which 4 directly relate to early diagnosis and intervention. These objectives were;

- Objective 1: Improving public and professional awareness and understanding of dementia.
- Objective 2: Good-quality early diagnosis and intervention for all.
- Objective 3: Good-quality information for those with diagnosed dementia and their carers.
- Objective 4: Enabling easy access to care, support and advice following diagnosis.

An implementation plan identified that these objectives should be achieved by the 31<sup>st</sup> of March 2015. Actions to implement the strategy commenced on the 1<sup>st</sup> of April 2009,

following which a joint commissioning framework was launched in June 2009. In July 2009 an announcement of the demonstrator sites for peer support and dementia advisors and a research summit for dementia occurred alongside the publication of a revised implementation plan which set targets and key dates for implementation. However, initial actions to implement the strategy were slow, with concern expressed that insufficient priority was being given to dementia with a lack of drivers such as effective leadership to ensure changes takes place (National Audit Office, 2010, Roberts, 2010).

Subsequently, a range of over-arching actions have occurred, which contribute to the implementation of the strategy and are relevant to the goals of earlier diagnosis and intervention. These have included:

- That local areas within England are required to develop tailored dementia strategies and associated implementation plans responsive to their local population,
- The appointment of a National Lead in Dementia, (January 2010) who provided leadership and support for shaping implementation of the Strategy, working with key partners at a national, regional and local level.
- And following this, the appointment of 3 Dementia Champions for the NHS, Social Care and the Independent Sector to provide leadership at local level, encourage and embed delivery at all levels; and support local accountability.
- The launch of a workforce development plan (2010)
- National Institute of Clinical Excellence (NICE) quality standards on dementia (2010) and the development of quality outcomes for people living with dementia (September 2010)
- The establishment of the NHS Quality Board to assess ways in which quality of care can be improved through improved commissioning and workforce development, and how this can be evidenced through quality data
- That specific targets for Dementia are embedded and further developed within the NHS operating framework from 2010/11 onwards. This continues to be a priority in 2013/14, with targets on early diagnosis and interventions following diagnosis.
- The development of a National Dementia Declaration which has involved over 100 national and regional organisations committing actions to improve the quality of life for people living with dementia from 2010 to 2014 and beyond. Progress on these commitments is monitored by the participating organisations

who have worked together to form the Dementia Action Alliance, which is hosted by the Alzheimer's Society

- The launch of the Prime Ministers Challenge on Dementia, which further refined the targets and actions required by 2015, to improve dementia care and research.

The evidence for progress in relation to 4 objectives relevant to earlier diagnosis is now described, including the further refinement of targets addressed in the Prime Ministers Challenge. However, as the date for implementation of the strategy is in 2015, it should be born in mind that the actions to achieve these objectives are still underway.

Furthermore, the majority of the literature reports on how the strategy was developed and describes its main features rather than assessing the progress that has been achieved.

***Objective 1: Improving public and professional awareness and understanding of dementia.***

This objective addresses improving awareness of dementia among both the general public and professionals. It was grounded in a recognition that considerable levels of stigma and social exclusion exist for people living with dementia (Moniz-Cook & Manthorpe, 2009). Consultation with people living with dementia and their families highlighted many examples of such stigma including the following comments;

*'It's as though that's it, you are dribbling and nodding, and that's Alzheimer's. That's the picture of Alzheimer's. But we are all sitting here talking perfectly normally. We have got Alzheimer's of some form; we are not nodding and dribbling.'* (person with dementia)

*'You don't get the same empathy that you would get if you were terminally ill.'*  
(carer) (DOH, 2009: 23)

As well as the stigma associated with dementia, the strategy highlighted that many people experienced delays in help seeking because symptoms were attributed to old age and therefore went unreported for considerable periods of time. Furthermore, the consultation also evidenced discrimination in access to health care and support, with many people experiencing considerable delays in receiving help and assistance due to the negative beliefs held by professionals without specialist training in dementia including family doctors (GP);

*'[The GP said] when you pass 70 you can expect to lose your memory a little bit.'*  
(person with dementia)

*'I consider that I didn't get a service from, not from the doctor, my own GP. From my own GP I just got patted on the head.'* (person with dementia)  
(DOH,2009:24)

Thus the strategy identified that awareness should be raised and that this should facilitate a greater level of knowledge about the benefits of a timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It should also encourage behaviour change in terms of appropriate help-seeking and help provision. (DOH, 2009:24). Four methods for achieving this aim were identified, as follows:

- Developing and delivering a general public information campaign.
- Inclusion of a strong prevention message that 'what's good for your heart is good for your head'.
- Specific complementary local campaigns.
- Targeted campaigns for other specific groups (e.g. utilities, public-facing service employees, schools, and cultural and religious organisations). (DOH, 2009: 24)

Following on from these original targets, further developments in the strategy resulted from discussions concerning the means through which inclusion of people with dementia can be achieved through community action. These discussions arose from concerns that raising awareness alone was not enough to address the many challenges that might prevent people living well with dementia. These challenges included considering the factors that prevent involvement and inclusion, and render it difficult for people with dementia and their families to meaningfully engage with everyday activities and interests that can sustain their lives. A report published in 2012 (Alzheimer's Society, 2012) highlighted the considerable difficulties that people experienced within their local communities, with nearly two thirds of people surveyed believing that their community has limited or no understanding of how to help them to live well with dementia. Furthermore, it identified that the general public believe that communities are less well prepared to support people who live with dementia, when compared with breast cancer, asthma and diabetes.

Consequently, in March 2012, the Prime Ministers Challenge set out further commitments to address these issues. These commitments involved creating dementia friendly communities that understand how to help and included that;



1. Dementia-friendly communities would be established across the country, identifying that by 2015, up to 20 cities, towns and villages will have signed up to become more dementia-friendly.
2. Leading national organisations would explore how they and others can play a part in creating a more dementia friendly society and raising awareness of dementia.
3. From autumn 2012, the Department of Health will invest in a nationwide campaign to raise awareness of dementia, to be sustained to 2015. This will build on lessons learned from previous campaigns and will inform future investment.
4. A major event would be held during the summer of 2012 bringing together UK leaders from industry, academia and the public sector, to take forward the PM's Challenge on Dementia.

### ***Progress on these targets***

Progress has occurred in the following areas:

#### *Public Awareness Campaigns*

In 2011, a public awareness campaign was launched, which focused upon raising awareness of the early signs of dementia. This campaign involved a television advert and leaflet which sought to inform people about spotting early signs and seeking help. The campaign was launched at Christmas 2011, because many people are visiting relations at this time of year. <http://www.dh.gov.uk/health/2011/11/spotting-the-signs-of-dementia>

In 2012, a further national campaign was launched by the Department of Health in collaboration with the Alzheimer's Society, with the aim of encouraging family members to have a conversation with a family member who they suspect might have early signs of dementia. The campaign provides advice on how to broach this difficult subject. <http://www.dh.gov.uk/health/2012/09/dementia-campaign>

Further national campaigns are planned until 2015.

To supplement this, local campaigns are also being implemented. See for example the South West initiative <http://www.dementiaawareness.co.uk> and <http://www.devon.gov.uk/index/socialcarehealth/dementia/dementia-awareness.htm> which seeks to increase awareness and develop services.

#### *Dementia Friendly Communities*

Within the prime minister's challenge (Department of Health, 2012) a target was set for up to 20 cities, towns and villages to volunteer to become dementia friendly, by 2015. Being dementia friendly, will be an accredited process delivered by the Alzheimer's

Society in conjunction with the Dementia Action Alliance in which towns and cities will be able to demonstrate increased awareness, understanding and support for people living with dementia and their family carers, [http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1843](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1843). Since its initial launch in March 2012, over 20 cities, towns and villages have committed to working towards becoming dementia friendly, and it is hoped that over 20 more will do so before 2015 (Department of Health, 2012b).

#### *Increasing Awareness in specific sectors*

Organisations such as the emergency services, financial institutions, leisure facilities, telecommunications, retail, education and transport have committed to finding ways of raising awareness and supporting people living with dementia and their families in their organisations. For example, the Fire and Rescue service have made a pledge on dementia involving increasing awareness among their staff and developing emergency cards for people with dementia to carry with them (Department of Health, 2012b).

Furthermore, 21 schools have committed to act as a lead group to develop awareness among children and young people aimed at reducing stigma and increasing opportunities for contact with people living with dementia. Following evaluation, it is hoped that a nationwide implementation of the programme of learning will occur from autumn 2013 (Department of Health, 2012b).

#### *Dementia Friends*

In the autumn of 2012, a further initiative was been launched to assist in raising awareness across all sectors of society. A target has been set to educate 1 million people by 2015 to become dementia friends. This initiative is designed to educate people about the needs of people with dementia, in order that they can provide support when people need it in their local community. This support could be as simple as providing assistance to find the right bus or to return home. The initiative is being managed by the Alzheimer's Society in England <http://www.dementiafriends.org.uk/siteHomePage>.

#### *Raising awareness among professionals*

Supporting people with dementia, particularly for non-specialist professionals such as family doctors is recognised as a particular challenge. It is acknowledged that the range of practitioners who come into contact with people with dementia need better education and training in order to enable them to achieve a better understanding and an increased level of skill in detecting and supporting people to live well with dementia. Various initiatives have been launched to increase awareness including

- Initiatives to embed dementia in the curriculum of all nurses and doctors in training,
- Providing an e-learning package to develop knowledge of dementia in health and social care staff,  
<http://www.scie.org.uk/publications/elearning/dementia/index.asp> which further supports the dementia gateway, an online resource for health and social care professionals <http://www.scie.org.uk/publications/dementia/index.asp>
- Development of a good practice exchange website to provide information sharing to health and social care professionals about what works  
<http://www.scie.org.uk/publications/dementia/innovation.asp>

Further developments are planned which relate to the next objective.

**Objective 2: Good-quality early diagnosis and intervention for all.**

This objective focused on the provision of an earlier and timely diagnosis and intervention for people with symptoms and their families. The drivers for this objective arose from a report which identified that only around one third of people with dementia ever received a diagnosis of dementia (National Audit Office, 2007). This report also highlighted that if a diagnosis is made, it is often made at a point when it is too late for the person to be involved in making choices and decisions about their lives and furthermore, that it frequently occurs in a crisis, which may have been prevented if the diagnosis and relevant support had been available earlier in their experience of dementia. Critical to an earlier diagnosis is the provision of appropriate, skilled and sensitive detection, assessment and diagnosis, followed by interventions. Consultations in the dementia strategy highlighted the considerable variability of experience of services, with some commenting that;

*'We had gone to him [the GP] for a lot of things and he was always telling [the person with dementia] that it was in his mind, he hadn't got these problems, he needed to pull himself together.'* (carer)

and

*'I've just been told "You've got Alzheimer's" and they walk out; [it] is absolutely bloody disgusting.'* (person with dementia)

*'I got the diagnosis on the phone by somebody I had never met telling me, "Your husband has Alzheimer's and vascular dementia." That was probably the worst possible way. That was absolutely infuriating.'* (carer) (Department of Health 2009: 31)

And some highlighting positive examples of practice from professionals, including;

*'[The GP] has been very positive in supporting both of us really. When this problem occurred he referred [the person with dementia] straight away to the memory clinic and stuff so he obviously saw something in her that he felt he should deal with straight away. When consultants and people have done tests on her and written to him he has always been in touch with us to let us know what is going on. He is very positive.'* (carer) (Department of Health, 2009: 32)

Therefore, a core aim of the National Dementia Strategy for England was to ensure that “effective services for early diagnosis and intervention are available for all on a nationwide basis” (Department of Health, 2009: 33). Thus the NDS (2009) identified that:

*“All people with dementia [are] to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area”. (p33).*

The NDS identified that this should be achieved through the commissioning of local services designed to provide appropriate, sensitive and effective assessment, diagnosis and intervention, assessing all new cases of dementia within a defined locality.

### ***Progress on this target***

A national audit of memory services (2011) explored progress on the establishment of memory services. This survey received an 80% response rate and identified that:

- 94% of respondents commission memory services, with a further 4% expressing the intention to do so in the future
- The number of people using memory services has increased from an average of 605 per organisation in 2008/9 to 951 in 2010/11.
- just under 32% of these memory services were accredited by the national programme of accreditation

<http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/qualityandaccreditation/memoryservices/memoryservicesaccreditation/msnapstandards.aspx>

However, as identified in the core target, a pathway of care is required, which additionally requires that the factors influencing referrals to memory services need to be addressed. Evidence that family doctors and their colleagues have difficulty in identifying early signs of dementia is widely recognised in the literature (Mitchell, *et al.* 2011, Belmin *et al.* 2012). This target and that of the target on workforce development

recognised the need to support family doctors and their colleagues in earlier and timely detection. Thus actions to address the challenges experienced in early detection are underway. Examples include;

- A randomised controlled trial with a pre-post intervention design to explore an intervention designed to support detection and management of people living with dementia by family doctors. Twenty primary care practices have participated. Researchers are examining “*whether the intervention is effective, pragmatic and feasible within the primary care setting*”. (Iliffe, et al. 2010: 1)
- Oxfordshire – Memory Assessment Services have been reviewed and diagnosis rates have improved to approx 50% (Raja, 2011)
- Poole – an increase in diagnosis rates in GP practices following a range of initiatives including workshops with GPs to raise awareness of importance of diagnosis, improvements in how diagnosis is recorded, and the commissioning of a Memory Adviser Service (Vitty, 2012)

Building upon this progress, the Prime Ministers Challenge (2012) has identified further initiatives to address rates of diagnosis. These are:

- The development of an analytical model toolkit to support the NHS to achieve a significant increase in diagnosis rates from the current 46%. It will support clinical commissioning groups to set a local ambition to improve their dementia diagnosis rate, commission sufficient memory services to deliver their ambition, and to track and demonstrate their progress
- From April 2013, as part of the NHS Health Check programme, people aged 65 to 74 will be given information at the time of the risk assessment to raise their awareness of dementia and the availability of memory services.

However, a recent inquiry has highlighted that variability in provision continues to be of concern (All Party Parliamentary Group, 2012). Concerns included; accessibility and responsiveness of primary care; willingness to approach a professional about memory difficulties; variability in memory services and availability of post diagnostic support. In this context, the review of the Prime Minister’s Challenge (Department of Health, 2012b), indicated that targets to improve practice would occur by;

- Restating the target to implement information and advice at the time of NHS checks for people aged 65 to 74
- Providing an innovation challenge prize which will make £1 million available to the NHS for projects that demonstrate innovative ways of achieving a dramatic

reduction in the proportion of people who have undiagnosed dementia, with evidence of a step change in the diagnosis rate and a strong service response.

- Working with the Royal College of Psychiatrists Memory Services National Accreditation Programme (MSNAP) to assure and improve the quality of memory services for people with memory problems and dementia. MSNAP engages staff in a comprehensive process of review, through which good practice and high quality care are recognised, and services are supported to identify and address areas for improvement.

<http://dementiachallenge.dh.gov.uk/2012/11/08/health-care-achievements>

- The NHS Outcomes Framework 2013/14 will be used to measure progress on diagnosis rates.
- The audit of memory services carried out in 2011 will be repeated
- The Quality Outcomes Framework is being re-evaluated to consider indicators for Dementia which will be evaluated for use in GP contracts in 2014/5

Diagnosis rates in England are currently thought to be at 42%, and the targets set within the Prime Ministers Challenge, clearly identify the need to increase diagnosis rates. It has been recognised that to achieve this, it is necessary to understand the reasons for the length of time it takes before people seek help, as well as to address the factors that influence the service that people receive when they approach a health professional. Efforts have therefore also focused on understanding the reasons for delays in help seeking, including funding research studies which have recently reported;

- Manthorpe, *et al.* (2011) The transition from cognitive impairment to dementia: older people's experiences (NIHR SDO)  
<http://www.kcl.ac.uk/sspp/kpi/scwru/pubs/2011/manthorpeetal2011transitionfinalreport.pdf>
- Broughton, N. Keohane, N. & Shorthouse, R. (2012). *A future state of mind: facing up to the dementia challenge*. London: Social Market Foundation, December 2012 <http://dementianews.wordpress.com/2012/12/20/facing-the-dementia-challenge-social-market-foundation>

Furthermore, it is recognised as necessary to address the quality of service provision (Alzheimer's Society, 2012), and as already highlighted, an aspect of this involves encouragement for memory services to sign up to the MSNAP process. MSNAP indicate that there are currently 39 accredited memory services, with a further 7 in the review stage. 145 memory services have registered on the list of registered memory services and clinics.

<http://www.rcpsych.ac.uk/quality/qualityandaccreditation/memoryservices/memoryservicesaccreditation/memoryservicesregister/registeredservices.aspx#northeast>

Evidence of progress to improve the quality of memory services also includes

- An initiative reported by Robinson, *et al.* (2010) in which person centred care communication skills were developed in an evidence based training workshop for old age psychiatrists, in which they explored how best to structure consultations with people with dementia. Following the workshop, the authors reported that 59% had made one or more changes to the structure of their consultations, 71% had used new communication skills and 56% had reflected further on their practice.
- The Deaf with Dementia Research study, exploring the development of a culturally appropriate assessment tool and documenting the experience of early diagnosis <http://www.nursing.manchester.ac.uk/deafwithdementia>

***Objective 3: Good-quality information for those with diagnosed dementia and their carers and Objective 4: Enabling easy access to care, support and advice following diagnosis.***

These two objectives are reviewed together, as support following diagnosis frequently combines both information giving and delivery of care support and advice.

Critical aspects of an earlier diagnosis involve the provision of support and interventions, with many people in the strategy consultation highlighting the absence of support, advice and information following diagnosis;

*'They didn't give me enough information. I came away thinking, "What do we do now, where do we go from here?" I have a prescription in one hand and a note for blood tests in the other and nobody has said what the CAT scan showed...nobody has given me that information. I am the person who is going to deal with [my husband].'* (carer) (Department of Health, 2009: 32)

And also the value of support when this is received:

*"Today I have met people who are in very much the same boat as I am with things they can and can't do...so for me it's a relief, a bloody relief to find that there are other people in the same boat as me.'* (person with dementia) (Department of Health, 2009: 32)

People living with dementia and their family members additionally identified that they would value an ongoing contact throughout the illness, from which they could access

support, information and advice, including knowing where to go for help. Previous research from the Alzheimer's Society has also identified the need for tailored information in order that people can access help and support. This has benefits including accessing personal budgets, sources of support including peer support and facilitating adjustment to the diagnosis (Alzheimer's Society, 2012).

Therefore, the National Dementia Strategy identified that the provision of accessible and high quality information which enables the person and their family to understand their illness and the services that are available to support them is required. This information should be provided following diagnosis and throughout their experience of living with dementia. Furthermore, they identified that each person with dementia and their family carers should have easy and direct access to a contact that can provide them with care, support and advice following diagnosis. These targets were to be delivered through;

- A review of existing relevant information sets.
- The development and distribution of good-quality information sets on dementia and services available, of relevance at diagnosis and throughout the course of care.
- Local tailoring of the service information to make clear local service provision. (Department of Health, 2009: 38)

And:

- The delivery of a new role, of dementia advisor, however;
- This is a new role and there will be a need first for the development and generation of demonstrator projects, and the piloting and evaluation of models of service provision prior to implementation.
- Following this, commissioning a local dementia advisor service to provide a point of contact for all those with dementia and their carers, who can provide information and advice about dementia, and on an ongoing basis help to signpost them to additional help and support.
- It was not intended that the role would replace existing care/case management structures, and that contact with the dementia advisor would be made following diagnosis. (Department of Health 2009: 33-4)



## **Progress on these targets**

### *Provision of easy and direct access to care and support following diagnosis*

In 2009, the tender for demonstrator sites for the Dementia Advisor role was launched. 22 demonstrator sites were awarded across England, delivered by a range of different organisations, including the Alzheimer's Society, health services, voluntary sector and local councils. The purpose of the demonstrator sites was to assess the impact of the dementia advisor service. The 22 sites have different models and it is expected that the National Evaluation of these sites, which is due to report in early 2013, will provide evidence concerning the effectiveness of the advisors. In addition, a number of demonstrator sites commissioned their own local evaluation of the service. See for example:

- Worcestershire Dementia Adviser Service Local Evaluation;  
[http://www.worcester.ac.uk/documents/Dementia\\_Adviser\\_Service\\_Final\\_Report.pdf](http://www.worcester.ac.uk/documents/Dementia_Adviser_Service_Final_Report.pdf)
- North Tyneside Dementia Advisor Service Pilot  
[http://www.linknorthtyneside.org.uk/Files/Project%20Space/DementiaAdvisorPilotreport\\_May11.pdf](http://www.linknorthtyneside.org.uk/Files/Project%20Space/DementiaAdvisorPilotreport_May11.pdf)
- Dementia Partnerships in Bristol and Somerset;  
<http://www.dementiapartnerships.org.uk/archive/demonstrator-sites/dementia-advisors/>

A number of services have commissioned a continuation of the service following the end of the funding for the demonstrator sites including

- Various areas covered by the Alzheimer's Society, including Worcestershire and Leicestershire
- Oxfordshire, <http://www.dementiaweboxfordshire.org.uk/dementia-advisers.html>
- Staffordshire, <http://www.approachstaffordshire.co.uk/news/16-dementia-advisors.html>
- Cheshire <http://www.ageuk.org.uk/cheshire/our-services/dementia-advisor-service-/>

## *Information*

Evidence of the review of existing information sets could not be found. However, a range of developments in information provision have occurred, adding to those already available, through a range of media including the internet. These include the following;

- Members of the Dementia Action Alliance have identified ways in which information is being made available through the journey of dementia. These include:
  - The Guideposts trust <http://www.dementiaweb.org.uk/>
  - BUPA portal [www.bupa.co.uk/understanddementia](http://www.bupa.co.uk/understanddementia)
- The Prime Ministers Challenge launched earlier in 2012, identified that the information offer pioneered by NHS South West, which was launched on 28 March 2012 will be rolled out across the south of England by the end of 2012. And then from April 2013, similar information will be locally developed and made available in all other parts of the country.  
<http://www.ourhealth.southwest.nhs.uk/dementia-care.html>
- The Department of Health has identified that it will also be setting out in the Care and Support White Paper further steps to ensure that all people receiving care and support get better information to support their care choices.
- The launch of the information strategy for health and social care, in which Information is regarded as a health and care service in its own right for all.  
[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_134205.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_134205.pdf)
- In the Prime Ministers Challenge, it was identified that information about dementia and risks of developing dementia will be given within the NHS health checks from aged 65 to 74, this will commence in 2013.
- Equality of access to information  
An equalities action plan (2011) was launched to supplement the equality impact assessment completed alongside the National Dementia Strategy and addressed information availability for specific groups of people whose information needs may go unrecognised, including;
  - people who have co-existing disabilities such as sight loss, hearing difficulties or deafness, health difficulties such as Parkinson's disease or stroke and intellectual disabilities such as Down's syndrome
  - people from migrant communities
  - Gender and sexuality
  - Younger people with dementia

- Carers of people living with dementia

The outcome of this exercise was that in the development of a commissioning pack to guide local commissioning of services, equality of access should be included as one of a number of considerations that should guide planning. Areas where information and research evidence were lacking were highlighted and recommendations were made to research funding bodies to ensure that equalities issues were addressed in their funding of research in this area. Additionally, recommendations were made concerning awareness raising in schools to address equality issues.

## Conclusions

The National Dementia Strategy for England has the goal of enabling people and their family carers to live well with dementia by addressing three main areas, summarised in the strategy as follows (Dept of Health, 2009: 21):

1. To encourage help-seeking and help-offering (referral for diagnosis) by changing public and professional attitudes, understanding and behaviour;
2. To make early diagnosis and treatment the rule rather than the exception; and achieve this by locating the responsibility for the diagnosis of mild and moderate dementia in a specifically commissioned part of the system that can, first, make the diagnoses well, second, break those diagnoses sensitively and well to those affected, and third, provide individuals with immediate treatment, care and peer and professional support as needed; and
3. To enable people with dementia and their carers to live well with dementia by the provision of good-quality care for all with dementia from diagnosis to the end of life, in the community, in hospitals and in care homes.

In order to achieve this, implementation has occurred at a national and local level. This has been underpinned by the development of leadership roles and strategies to embed change within local and national agendas and quality outcomes. This has included providing a national clinical lead role in dementia, 3 dementia champions within the NHS, Social Care and the Independent Sector and the development of the National Dementia Declaration which brings together over 100 national, regional and local organisations who have committed actions to improve the quality of life of people living with dementia.

4 objectives of the strategy have directly addressed early diagnosis and intervention, with ongoing reviews resulting in revised plans to meet these objectives. The first

objective of improving public and professional awareness has been addressed in a number of ways. Core to this objective is challenging the stigma associated with dementia, which influences help seeking and subsequently opportunities to live well with dementia. Stigma is being challenged through national and local campaigns which are being delivered until 2015. It is also occurring through the development of dementia friendly communities who can challenge the stigma associated with acknowledging that a problem might exist and enable people to live well with dementia. The knowledge and attitudes of professionals are being addressed through workforce development and through targeted specific learning opportunities and toolkits designed to enhance knowledge and practice in Dementia.

Progress on improving diagnosis rates has achieved a modest increase from less than 1/3<sup>rd</sup> of people in 2007, to a national average of 46% in 2013. Subsequently targets and associated actions have been set to further increase this number, through such strategies as providing information and advice about memory difficulties in the health checks of people aged 65 to 75 and the development of an analytical toolkit to support increase in diagnosis rates. The delivery of actions on these targets will need to take into account recent reports concerning the complex factors associated with delays in help seeking.

Memory assessment services now exist in a large proportion of localities in England, with some identifying increases in numbers of people coming forward for diagnosis, above that of the national average of 46%. Further progress is needed to establish complete coverage of memory assessment services across all localities within England. Additionally, while some areas show significant improvements in rates of diagnosis others do not, and it is recognised that this considerable variability is unacceptable. Thus this objective also identifies the need to improve the quality of the diagnostic process. This is being addressed in part through a national accreditation programme to assure and improve the quality of memory services for people with dementia and their families with all services in England being encouraged to participate.

Research indicates that the provision of information, intervention and advice following diagnosis would appear to be a critical factor influencing the wellbeing of people living with an early and timely diagnosis of dementia and their families. Thus the third and fourth objectives of the NDS are of considerable importance. Progress has been achieved in regard to the pilot of a role which will provide an ongoing contact through the experience of dementia. The evaluation of the demonstrator sites for the role of dementia advisor are due to report in early 2013. While the funding for the demonstrator sites has ended, some areas have continued and expanded the services being delivered within this role. Local evaluations have given positive indicators of the

value of dementia advisors, although it is evident from these reports, that a range of factors are critical to their ongoing success, including the receptiveness of existing health and social care professionals and the communities in which they are working; the skills and knowledge of the persons employed in that role; the availability of resources that can be accessed by people living with dementia and the organisational structures within which they operate.

A wide range of health and social care professionals within the statutory and independent sector provide information for people living with dementia and their families. A review of existing information sets could not be identified, however a range of organisations have developed information resources to be accessed by people living with dementia and their families. A variety of actions are underway to provide information to people living with dementia and their families, including plans for the national adoption of a regionally developed information 'offer' and to provide such information in specific health checks and contacts with professionals.

# Results – Early Diagnosis Questionnaire

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As part of Work Package 5 an analysis of health care systems for early diagnosis was undertaken, based on a questionnaire sent to all 27 European Union countries. The outcome from the questionnaires was used along with the literature review to formulate recommendations for improving early diagnosis in ambulatory and nursing home settings.

## **Analysis**

The results from the questionnaire were considered separately for each of the six sections within the questionnaire. The analysis methods used for the questionnaire varied depending on the individual question, with some questions having their results presented from a country perspective and others from a response perspective, depending on what the aspect each question was addressing. The wide range of responses from countries that are often very different also meant that using the same method for each question was not possible, but four of the main approaches used are listed here. The analysis carried out was mainly descriptive rather than statistical.

### **Standardising responses**

The countries in the EU are generally very different in terms of both their geographical sizes and populations, so it was difficult to compare responses that are based on raw numbers. To make comparisons more meaningful responses involving population figures in different age ranges were converted into a percentage of the total country population, and the numbers of professionals in different roles were converted into the number per 1000 people aged 65+, as this is the target patient group we are interested in. Similarly, the numbers of memory clinics and services were converted into the number of people aged 65+ per clinic or service to allow fairer comparisons to be made.

### **Ranking countries**

Although countries are not ranked in terms of being better or worse than others, the results for some questions are presented in an ordered fashion to show the range of responses. An EU median value is also provided for reference in these cases.

### **Grouping countries**

For questions where there was a set of standard responses to choose from, countries are grouped together if they responded in the same way. For example, countries that have National Official Guidelines for Diagnosis are grouped separately from those without such guidelines in place.

## Frequency of responses

Some questions allow countries to select or provide multiple answers, and in these cases the results are generally presented as frequency charts to show which were the most common responses.

## Response rate

Thanks to the repeated efforts of the ADS team and the regional coordinators, the response rate gradually increased, but at a slower rate than anticipated. A timeline indicating when responses were received, in relation to the different phases of the project, is shown in Table 11. After getting a response from Poland in mid-July 2012, one from Italy at the end of August and additional information for individual questions in September – 11 months after the original deadline – questionnaire responses had been received by 24 of the 27 EU Member States. This represents a response rate of 89%.

Table 11: Response timeline

| Phase   | Time point     | Actions/Comments   | Number of questionnaire responses received |
|---------|----------------|--|--|
| Phase 1 | June 2011      | Original questionnaire designed and sent out via regional coordinators               | -  |
|         | October 2011   | Original questionnaire deadline  | -  |
|         | December 2011  | ADS joined ALCOVE project  | 5 in total                                 |
| Phase 2 | January 2012   | Questionnaire redesigned   | -  |
|         | February 2012  | ADS contacted countries directly. Regional coordinators prompted to remind countries | 15 in total                                |
|         | May 2012       |  | 20 in total                                |
|         | July 2012      |  | 23 in total                                |
|         | September 2012 |  | 24 in total                                |

The countries that had not responded by September 2012 are highlighted in orange in Table 12. It can be seen that the Southern region had the worst individual response rate at 67%. Unfortunately, the reason for the individual countries failing to respond is not known, and it would be wrong to make assumptions without further information.

*Table 12: Highlighting the EU Member States that did not respond to the Early Diagnosis questionnaire*

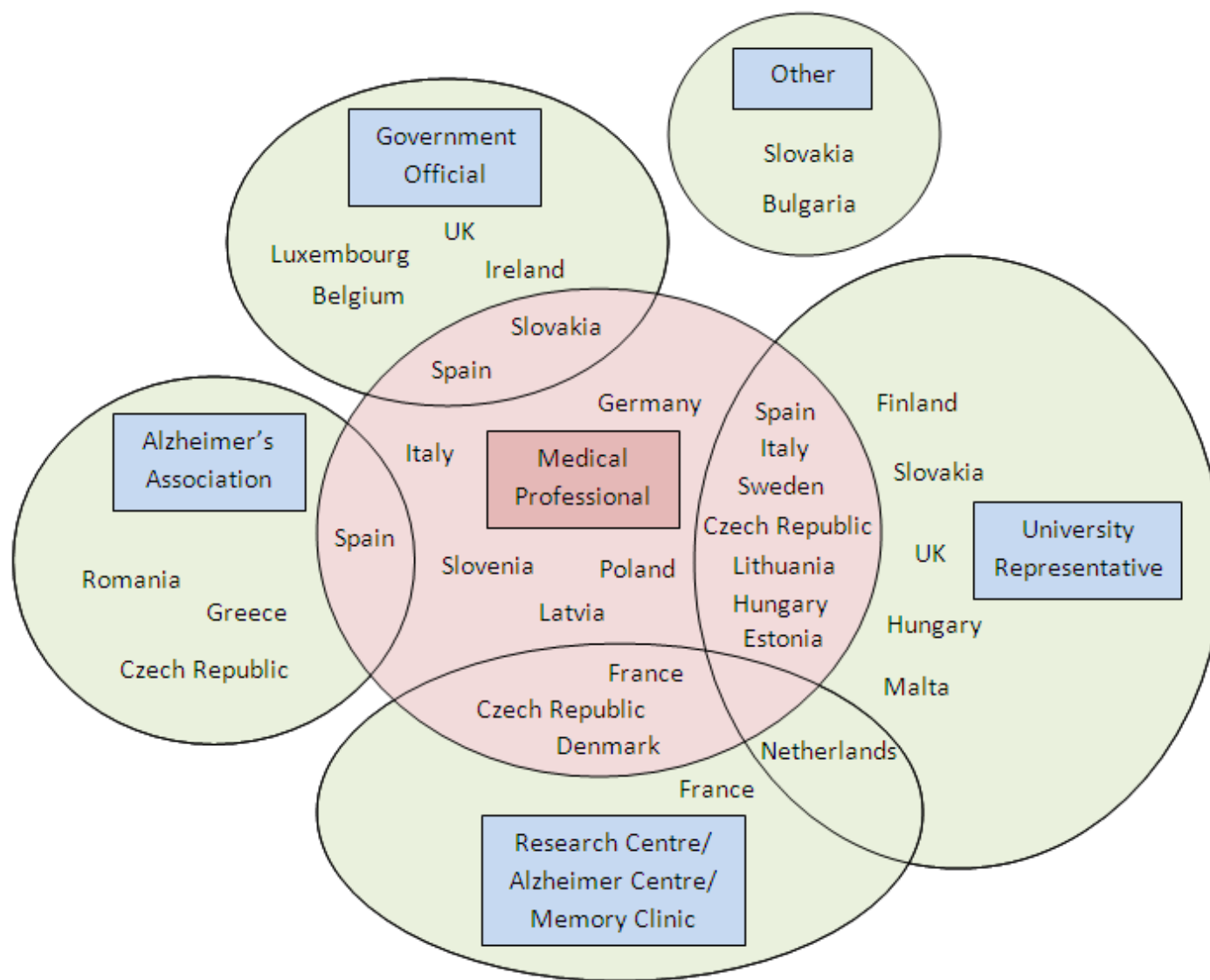
| Central                      | Eastern                       | Northern                      | Southern                     | Western                       |
|------------------------------|-------------------------------|-------------------------------|------------------------------|-------------------------------|
| Austria                      | Estonia                       | Denmark                       | Cyprus                       | Belgium                       |
| Bulgaria                     | Latvia                        | Finland                       | Greece                       | France                        |
| Czech Republic               | Lithuania                     | Germany                       | Italy                        | Ireland                       |
| Hungary                      | Poland                        | Netherlands                   | Malta                        | Luxembourg                    |
| Slovakia                     | Romania                       | Sweden                        | Portugal                     | United Kingdom                |
| Slovenia                     | -                             | -                             | Spain                        | -                             |
| Regional response rate = 83% | Regional response rate = 100% | Regional response rate = 100% | Regional response rate = 67% | Regional response rate = 100% |

## Questionnaire respondents

At the beginning of the questionnaire basic information was collected about the person(s) who completed the questionnaire. The responses indicated that there was a lot of variation within and between countries in terms of who was responsible for the questionnaire, including medical professionals, academics and government officials. The types of organisation represented by the people who completed the questionnaires are shown in Figure 5. For some countries multiple responses were received or a questionnaire was completed by more than one person, which is why some countries are featured more than once.



Figure 5: Organisations of questionnaire respondents



## Issues arising

Although receiving responses from 24 countries is very good, a number of issues arose when looking through the responses, which need to be raised to ensure that the subsequent analysis is put in context.

- Multiple responses – for some countries responses were received from more than one source. This can be a problem when the responses to individual questions are not the same, or are even directly contradictory. Where multiple responses were received a common answer was used where possible or the lower of any ordered options was used, otherwise an ‘unclear’ response was recorded. A summary of the number of responses for each country is given in Table 13;
- Inconsistent implementation of the questionnaire – This was an issue for Spain in particular, as it appears that Spain generated its own version of the questionnaire. This meant that additional information was included in the initial covering description at the start of the questionnaire, some of the questions were not presented in the same way as in the official questionnaire, and they were sometimes not in the same order. In addition, multiple responses were received, with some respondents providing answers for individual areas of Spain, e.g. the Basque country, rather than for Spain as a whole. This made it difficult to analyse as it was not always clear what area a response related to. This meant that a ‘best guess’ was often used to reach a consensus response;
- Missing responses – Many questionnaires had occasional blanks where answers were not provided;
- Partially completed questionnaires – While most questionnaires had individual questions that were not answered, some were only partially completed. For example, the first two or three sections may be filled in, but the remainder of the questionnaire was blank. Where this happened, it was unclear if it was because countries lost interest, didn’t know the answers, did not understand what was being asked, or simply missed a section. A summary of which countries gave partial responses is given in Table 13;
- Invalid responses – Some questions were comprised of multiple parts, with later parts only being completed if the answer to an earlier part was ‘Yes’. In spite of these questions being clearly marked, some countries completed the later parts although they said ‘No’ to the first part. This was mainly an issue for a question relating to advance statements and advance directives, where some countries said what they covered despite having previously said that they did not have them in place. Where this occurred,

the subsequent answers were considered to be invalid and were not included in the analysis;

- Approximate or vague responses – Although not many questions required a numerical answer, it was seen for those that did that responses from some countries were often vague, approximate or a range. For example 2000-3000 neurologists. Conversely, responses from other countries were very specific. To try and get some form of consistency, where ranges were given the mid-point was taken as the answer if a specific figure was required for comparison purposes.

*Table13: Countries returning multiple and/or partial questionnaire responses*

| More than one response per country | Partial responses (partial/total) |
|------------------------------------|-----------------------------------|
| Denmark (2)                        | Bulgaria (1/1)                    |
| France (2)                         | Hungary (1/1)                     |
| Ireland (2)                        | Slovakia (1/3)                    |
| Latvia (2)                         | Spain (3/8)                       |
| Romania (2)                        |                                   |
| Slovakia (3)                       |                                   |
| Spain (8)                          |                                   |

A summary of the response rates per section of the questionnaire is given in Table 14, and shows that the partial response from Bulgaria consisted of just the first section of the questionnaire. As it was the only response from that country, it was not possible to use other responses to fill in any gaps. Similarly, the only response from Hungary did not complete the final section, and the questions in this section remained unanswered.

*Table 14: Summary of response rates per section*

| Section              | Number of countries answering at least one question | Number of countries not answering any questions |
|----------------------|---|---|
| Country Data         | 24  | 0   |
| Diagnosis            | 23  | 1 (Bulgaria)                                    |
| Theory vs. Practice  | 23  | 1 (Bulgaria)                                    |
| Legal Framework      | 23  | 1 (Bulgaria)                                    |
| Health Organisations | 23  | 1 (Bulgaria)                                    |

|   |    |                       |
|---|----|-----------------------|
| Relationships between GPs and specialists | 22 | 2 (Bulgaria, Hungary) |
|---|----|-----------------------|

In addition to the previous issues, some responses were considered to be ‘outliers’ in that they were a lot higher or lower to those from other countries. While it was not possible/practical to verify all responses (and indeed would negate the whole point of getting countries to complete their own questionnaires), a few outliers were investigated using the Internet to see if they were actually in the right ballpark. These responses are highlighted where appropriate. Unless otherwise stated, all responses were accepted at face value.

## Country data

### How many people are there aged over 65 in your country?

Number of responses: 24

Number of missing responses: 0

Variations in responses:

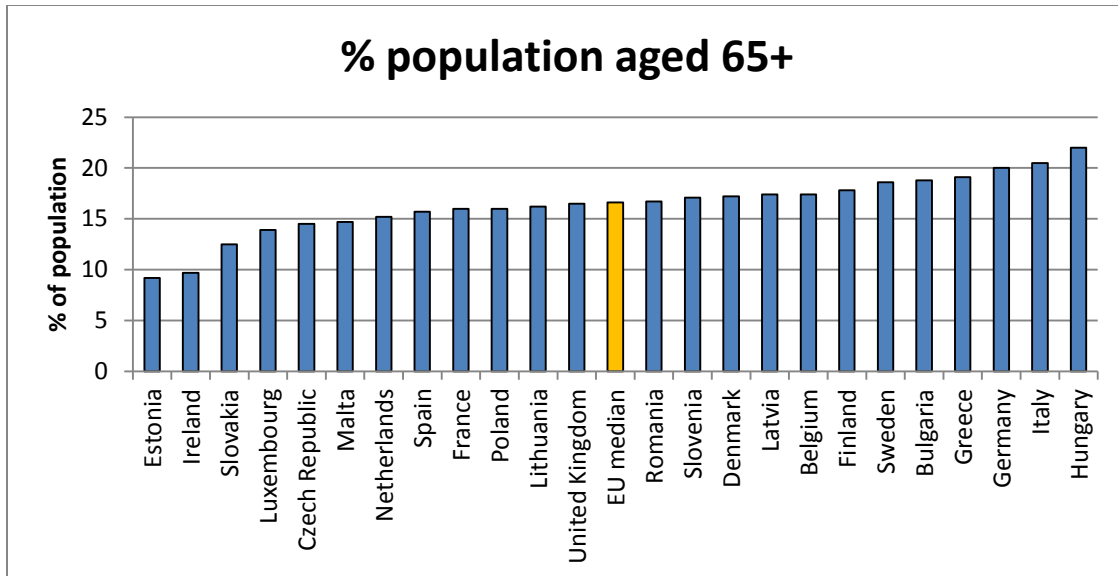
- Specific number
- Approximate number
- Percentage

As the actual number of people is fairly meaningless when comparing countries with different populations, the questionnaire results were converted to a percentage of the population for each country. This was done using the population figures given on the European Union website<sup>1</sup> unless a population and/or percentage were given as part of the questionnaire response. These converted responses are shown in Figure 6.

*Figure 6: % population aged 65+*

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<sup>1</sup> [http://europa.eu/index\\_en.htm](http://europa.eu/index_en.htm)



It can be seen from Figure 6 that although there is some variation between countries, an older population is a common issue across the EU with almost all responses in the 10-20% range.

### How many people are there aged over 75 in your country?

Number of responses: 22/24

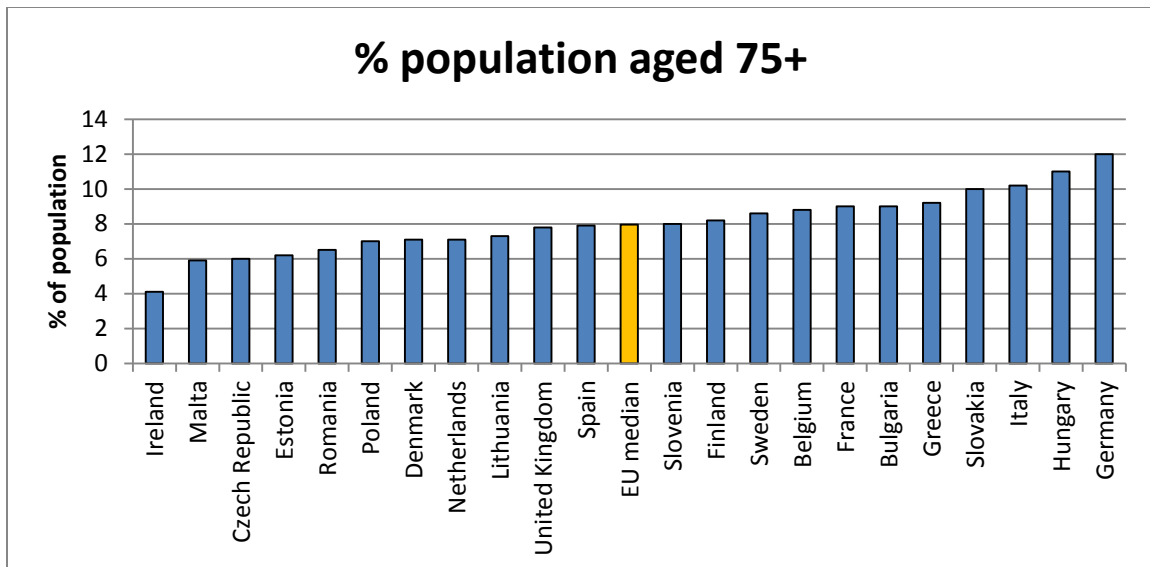
- Latvia and Luxembourg both said that no data was available

Variations in responses:

- Specific number
- Approximate number
- Percentage

As with the previous question, the responses were converted to percentages of the population for fairer comparison. It can be seen from Figure 7 that for almost all countries between 6% and 10% of their population is aged 75+, reinforcing the fact that all countries have to cope with an ageing population.

*Figure7: % population aged 75+*



### How many people are there aged over 85 in your country?

Number of responses: 22/24

- Latvia and Luxembourg both said that no data was available

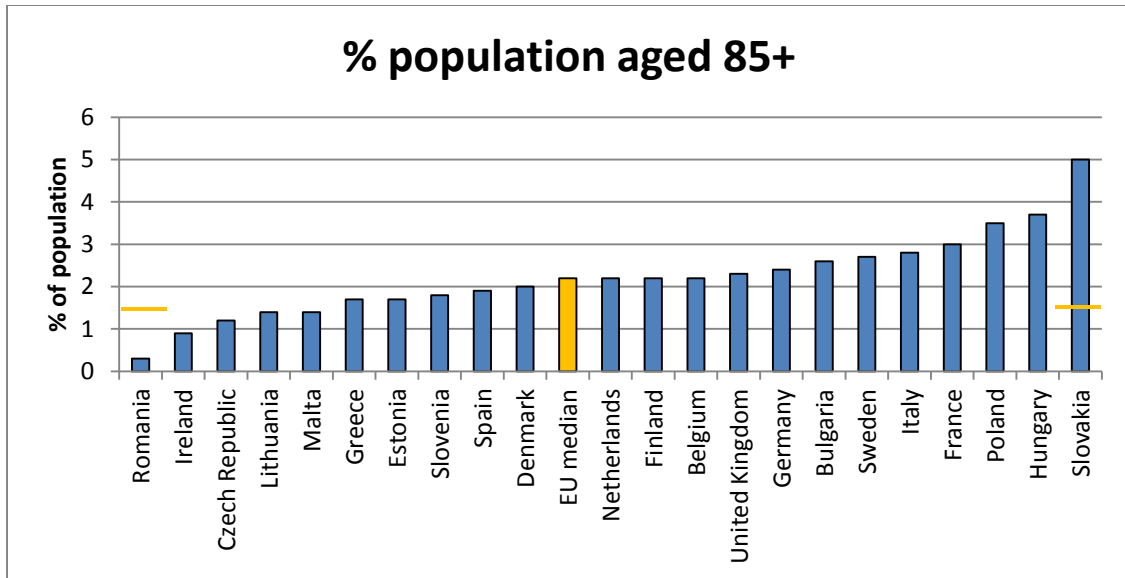
Variations in responses:

- Specific number
- Approximate number
- Percentage

As with the previous questions, the responses were converted to percentages of the population for fairer comparison. From Figure 8 it can be seen that the result for Romania is a lot lower than for other countries, and Slovakia is a lot higher, but this could be due to inaccuracies in the responses given. Overall, most countries have approximately 1.5-3% of their population aged 85+.

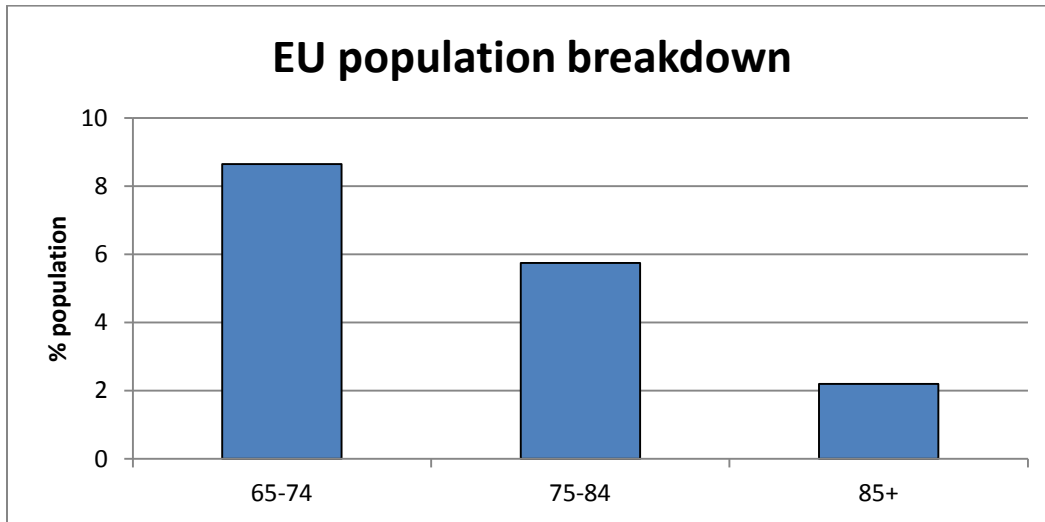
- Response verification for Slovakia – information found on the Internet indicates that 5% is to be too high. A value closer to 1.1-1.5% may be more appropriate. This is shown as the orange line for Slovakia in Figure 8.
- Response verification for Romania – information found on the Internet indicates that a value closer to 1.5% may be more appropriate. This is shown as the orange line for Romania in Figure 8.

Figure 8: % population aged 85+



Taking the EU median values calculated based on the responses, the overall position for the EU is shown in Figure 9. It indicates that approximately half of the 65+ population are actually also 75+, with around a quarter of those being 85+. This highlights that across Europe older people represent a significant proportion of the population, and issues affecting people in this age range cannot be ignored.

Figure 9: EU population breakdown (based on median values)



### How many neurologists are there in your country?

Number of responses: 23

Number of missing responses: 1

- This question was left blank by Ireland

Variations in responses:

- Specific number
- Approximate number
- Range

As with population figures, the actual number of neurologists does not allow for a fair comparison between countries of different sizes. The values were therefore converted to the number of neurologists per 1000 people aged 65+, based on the responses given in the first question. Where only a percentage was given, the number of people aged 65+ was calculated based on the values given on the European Union website.<sup>2</sup> The population numbers were rounded to the nearest 1000.

As can be seen from Figure 10, there is a lot of variation between countries, ranging from 0.06 (UK) to 1.4 (Greece). While this could suggest that the role of Neurologist is at a different stage of development in different countries, it could also indicate that the role is defined differently as well.

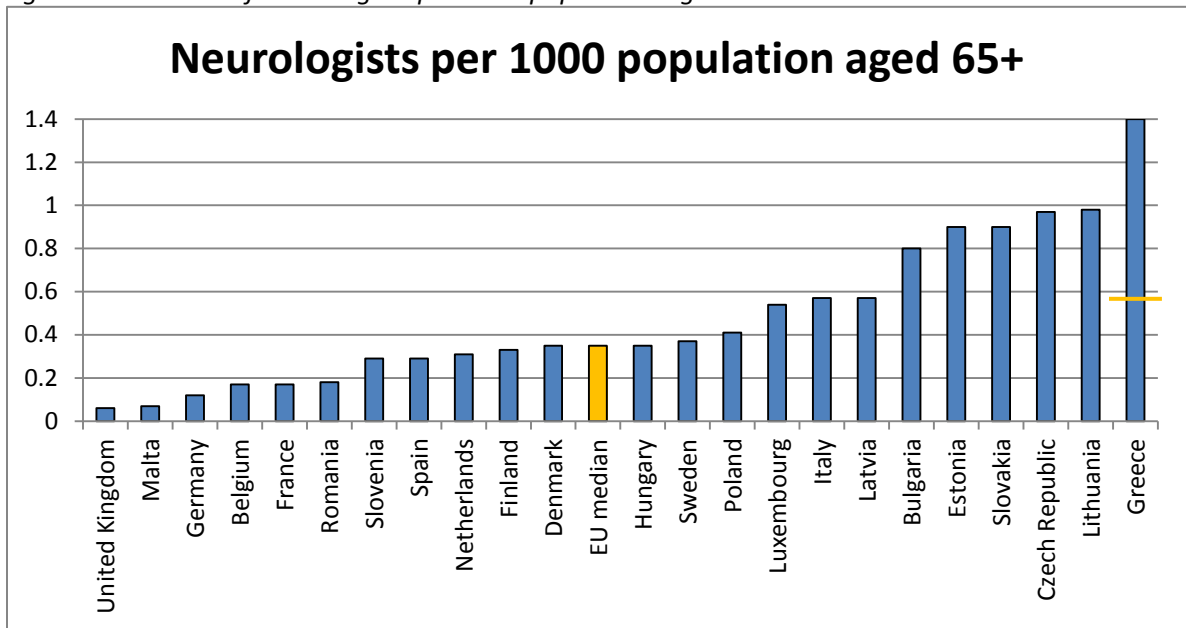
- Response verification for Greece – information found on the Internet indicates that 3,000 Neurologists (equating to 1.4 per 1000 aged 65+) appears to be too high. A value closer to 1,200 (equating to 0.56 per 1000 aged 65+) may be more appropriate. This is shown as the orange line for Greece in Figure 10.

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<sup>2</sup> [http://europa.eu/index\\_en.htm](http://europa.eu/index_en.htm)



Figure 10: Number of Neurologists per 1000 population aged 65+



### How many geriatricians are there in your country?

Number of responses: 22/24

- Estonia indicated that the role of geriatrician is not recognised
- Slovenia gave an answer of 0

Variations in responses:

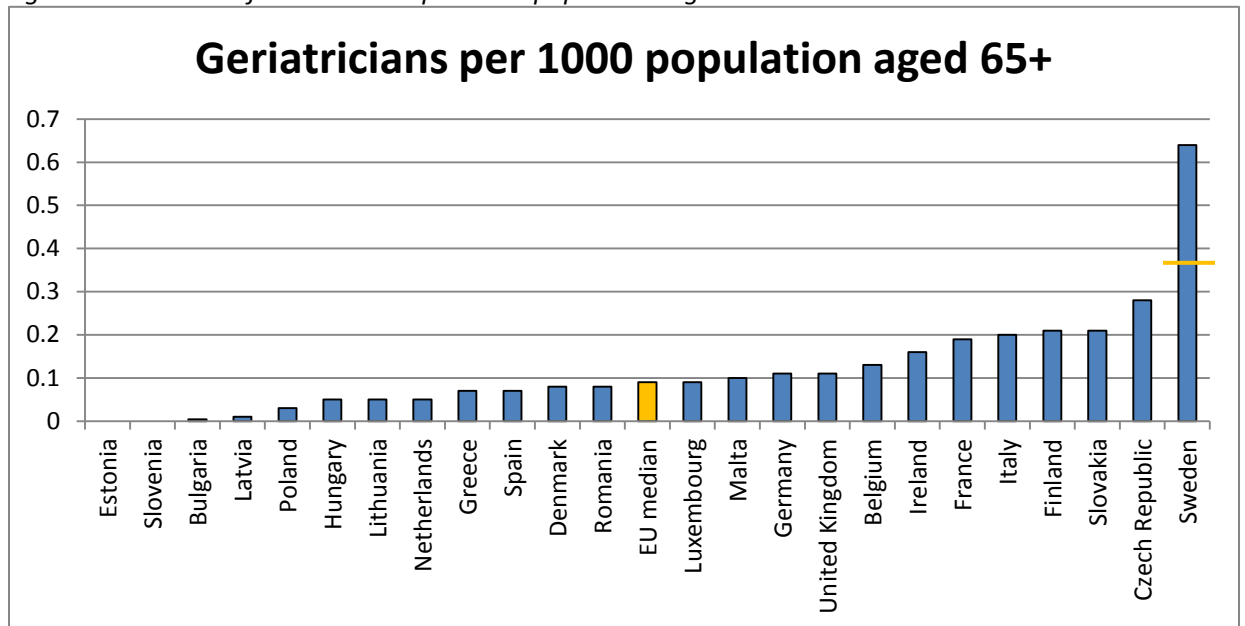
- Specific number
- Approximate number
- Range

The responses were again converted to the number of neurologists per 1000 people aged 65+. From Figure 11 it can be seen that Sweden is a lot higher than the other countries, being more than double the next highest response. Overall, the figures are a lot lower than those for Neurologists, suggesting that Geriatrician could be a newer or less well-recognised role in some countries.

*Response verification for Sweden – information found on the Internet indicates that 1,124 Geriatricians (equating to 0.64 per 1000 aged 65+) appears to be too high. A value closer to 650 (equating to 0.37 per 1000 aged 65+) may be more appropriate. This is shown as the orange line for Sweden in Figure 11*

- Figure .

Figure 11: Number of Geriatricians per 1000 population aged 65+



## How many psychiatrists are there in your country?

Number of responses: 24

Variations in responses:

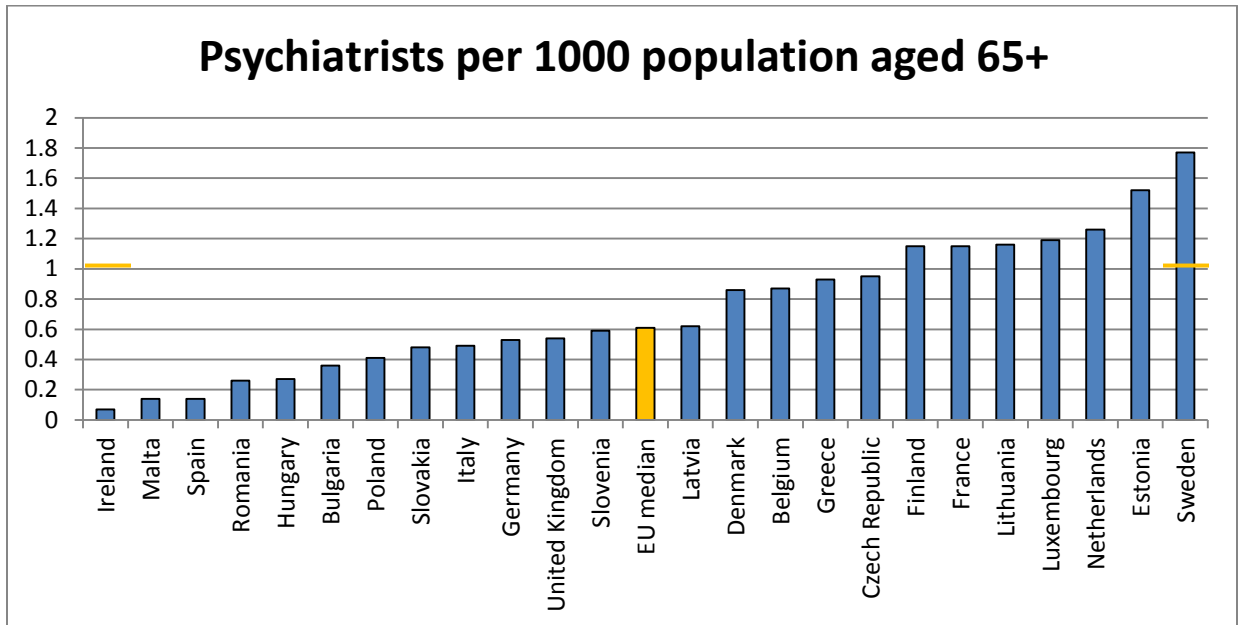
- Specific number
- Approximate number
- Range

The range of converted responses is quite large, from 0.07 (Ireland) to 1.77 (Sweden), with an EU median of 0.61. The values are generally higher for Neurologists and Geriatricians, suggesting that the role of Psychiatrist may be more established in many countries.

- Response verification for Sweden – information found on the Internet indicates that 3,096 Psychiatrists (equating to 1.77 per 1000 aged 65+) appears to be too high. A value closer to 1,800 (equating to 1.03 per 1000 aged 65+) may be more appropriate. This is shown as the orange line for Sweden in Figure 12.
- Response verification for Estonia – information found on the Internet indicates that 187 Psychiatrists (equating to 1.52 per 1000 aged 65+) appears to be about right.
- Response verification for Ireland - information found on the Internet indicates that 30 Psychiatrists (equating to 0.07 per 1000 aged 65+) appears to be too low. A value closer to 450 (equating to 1.03 per 1000

aged 65+) may be more appropriate. This is shown as the orange line for Ireland in Figure 12.

Figure 12: Number of Psychiatrists per 1000 population aged 65+



### How many old age psychiatrists are there in your country?

Number of responses: 11/12

- Czech Republic said 'Not known'
- Italy said that this question was not applicable, indicating that the profession is not recognised there

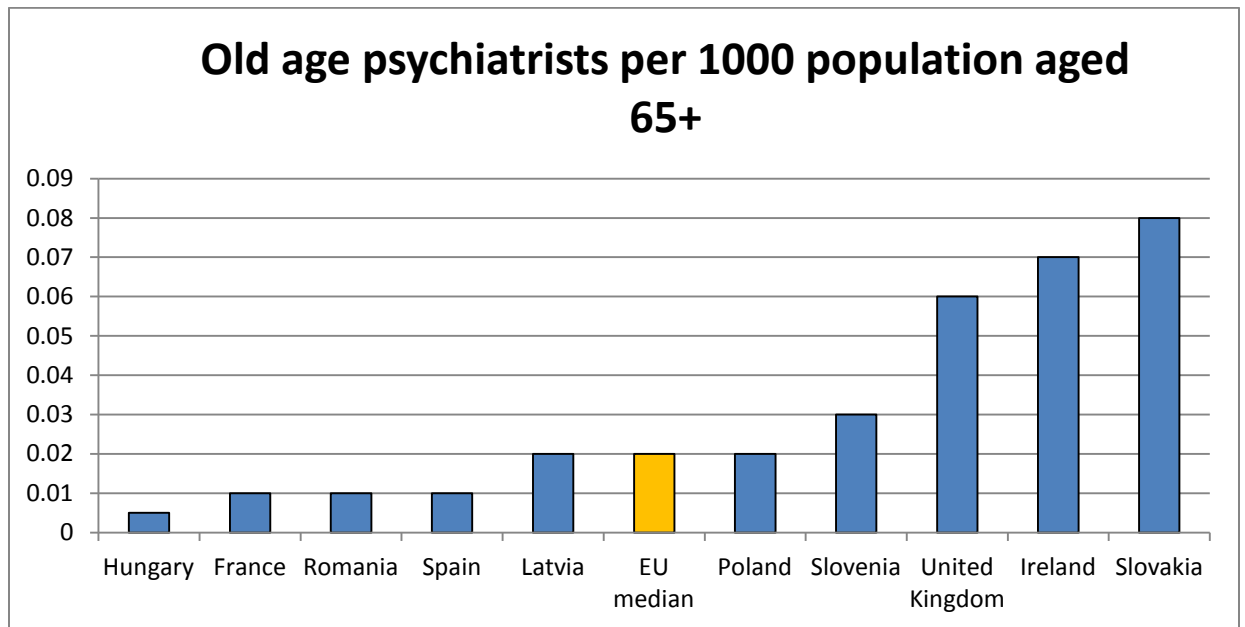
Number of missing responses: 12 – this question was only added in the new version of the questionnaire, so people completing the original version would not have answered it.

Variations in responses:

- Specific number
- Approximate number

Although responses to this question were only received from about half of the countries, the pattern seen in Figure 13 indicates that the number of old age psychiatrists is generally very low across the EU.

Figure 13: Number of Old Age Psychiatrists per 1000 population aged 65+



### How many GPs are there in your country?

Number of responses: 23

Number of missing responses: 1

- This question was left blank by Slovenia

Variations in responses:

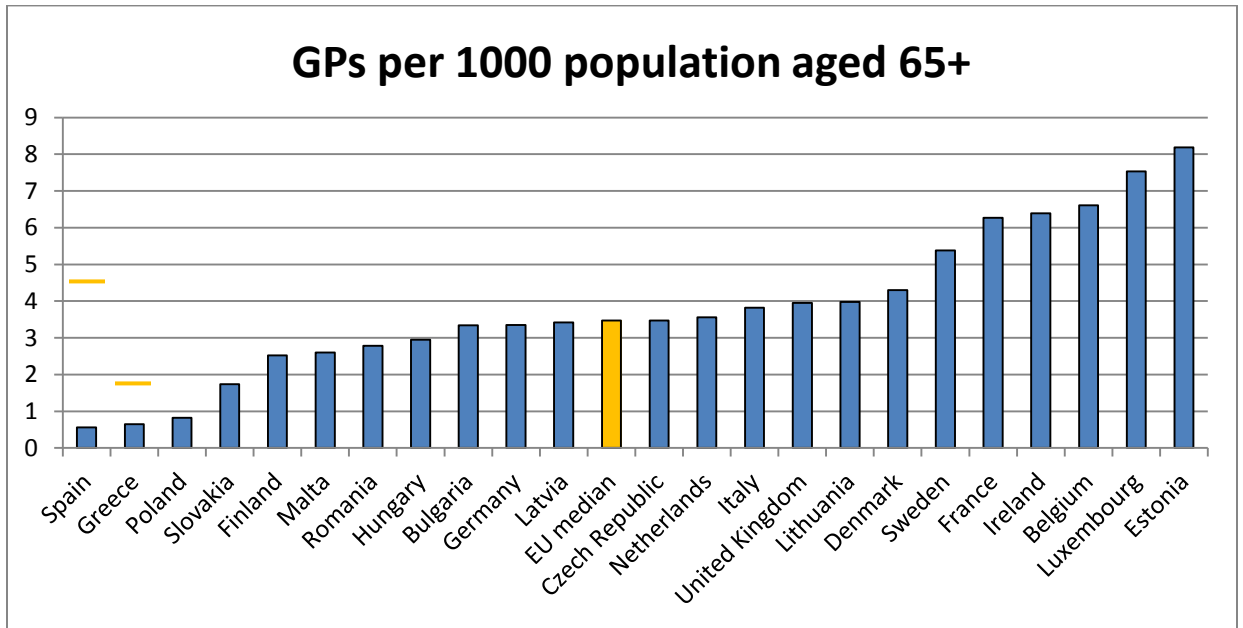
- Specific number
- Approximate number
- Number per 100,000

As shown in Figure 14 the range of responses is quite large, from 0.56 (Spain) to 8.19 (Estonia).

- Response verification for Estonia – information found on the Internet indicates that 1,007 GPs (equating to 8.19 per 1000 aged 65+) appears to be about right.
- Response verification for Spain – information found on the Internet indicates that 4,000 GPs (equating to 0.56 per 1000 aged 65+) appears to be too low. A value closer to 33,000 (equating to 4.58 per 1000 aged 65+) may be more appropriate. This is shown as the orange line for Spain in Figure 14.

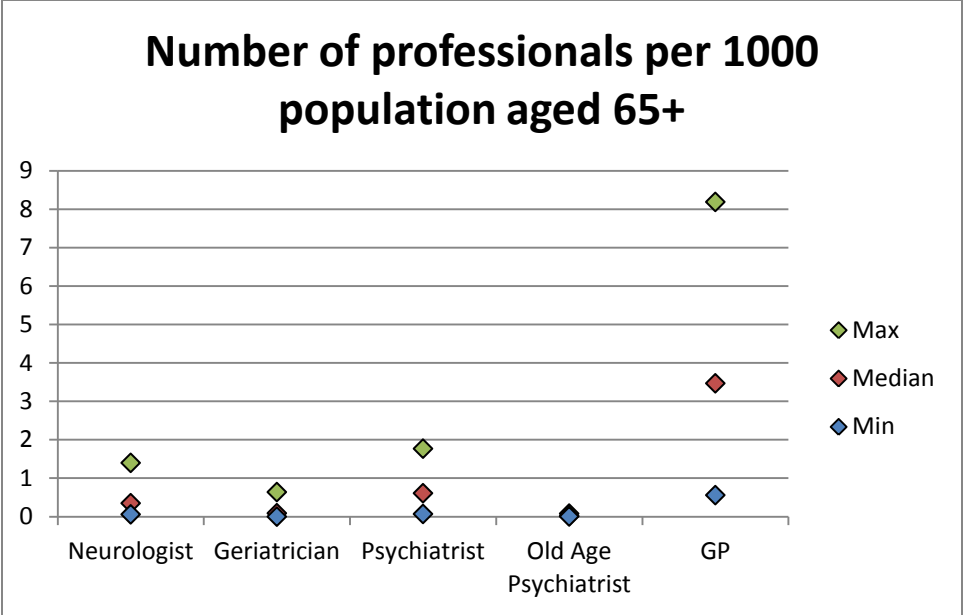
- Response verification for Greece – information found on the Internet indicates that 1,400 GPs (equating to 0.65 per 1000 aged 65+) appears to be too low. A value closer to 3,700 (equating to 1.73 per 1000 aged 65+) may be more appropriate. This is shown as the orange line for Greece in Figure 14.

Figure 141: Number of GPs per 1000 population aged 65+



A comparison of the different professionals is provided in Figure 15, and shows that overall GP is the most widespread/recognised role, and Old Age Psychiatrist is the least common/recognised role. This is not overly surprising, as the order of the professions reflects the level of specialism, i.e. GP is the most general/least specialised, and you would expect there to be fewer people in the more specialist professions.

Figure15: Summary of professionals per 1000 population aged 65+



## **What percentage of Neurologists work in hospital or ambulatory/community settings?**

Number of responses: 14/21

- Luxembourg, Denmark and Greece said no data available or unknown
- Germany responded ‘?’
- Netherlands said most work in both settings
- Malta said all work in both settings
- Sweden said most are employed by hospitals, but did not give a figure to use

Number of missing responses: 3

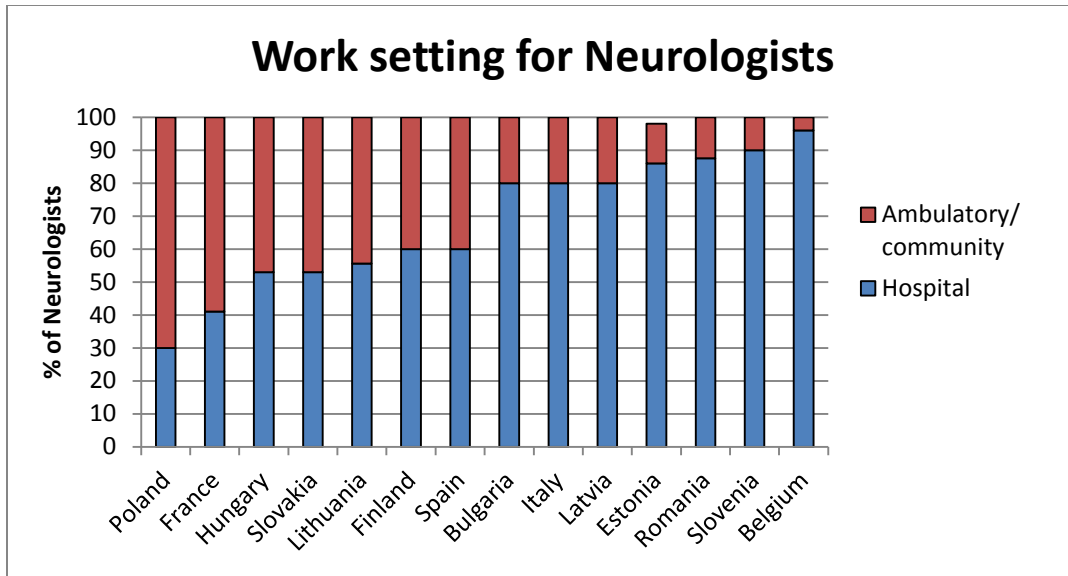
- This question was left blank by the Czech Republic, Ireland and the United Kingdom

Variations in responses:

- Figures for one setting
- Figures for both settings
- Approximate figures
- The number of professionals in the different settings

From Figure 16 it can be seen that the responses were quite varied for different countries, but generally neurologists were more likely to work in hospitals rather than in an ambulatory/community setting.

*Figure 162: Work setting for Neurologists*



### What percentage of Geriatricians work in hospital or ambulatory/community settings?

Number of responses: 13/20

- Luxembourg, Denmark and Greece said no data available or unknown
- Estonia indicated that this was not relevant as the role of Geriatrician is not recognised
- Netherlands said most work in both settings
- Malta said all work in both settings
- Sweden said most are employed by hospitals, but did not give a figure to use

Number of missing responses: 4

- This question was left blank by Bulgaria, Czech Republic, Slovenia and the United Kingdom

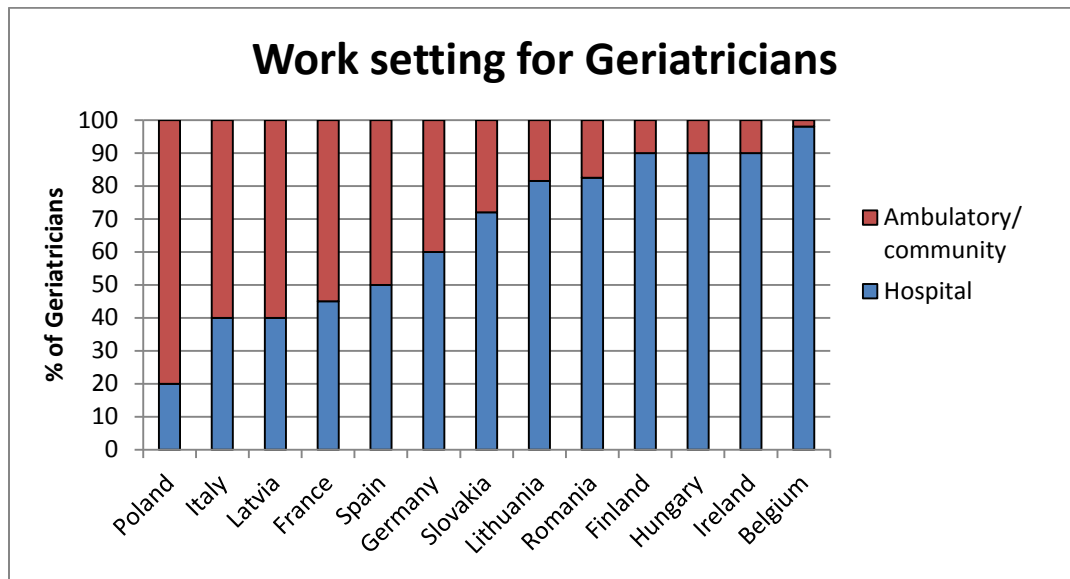
Variations in responses:

- Figures for one setting
- Figures for both settings
- Approximate figures
- The number of professionals in the different settings

As with neurologists, the responses for geriatricians are very varied, with the majority of countries reporting that most geriatricians work in a hospital setting.



Figure 173: Work setting for Geriatricians



### What percentage of Psychiatrists work in hospital or ambulatory/community settings?

Number of responses: 15/21

- Luxembourg, Denmark and Greece said no data available or unknown
- Germany responded ‘?’
- Malta said all work in both settings
- Sweden said most are employed by hospitals, but did not give a figure to use

Number of missing responses: 3

- This question was left blank by the Czech Republic, Ireland and the United Kingdom

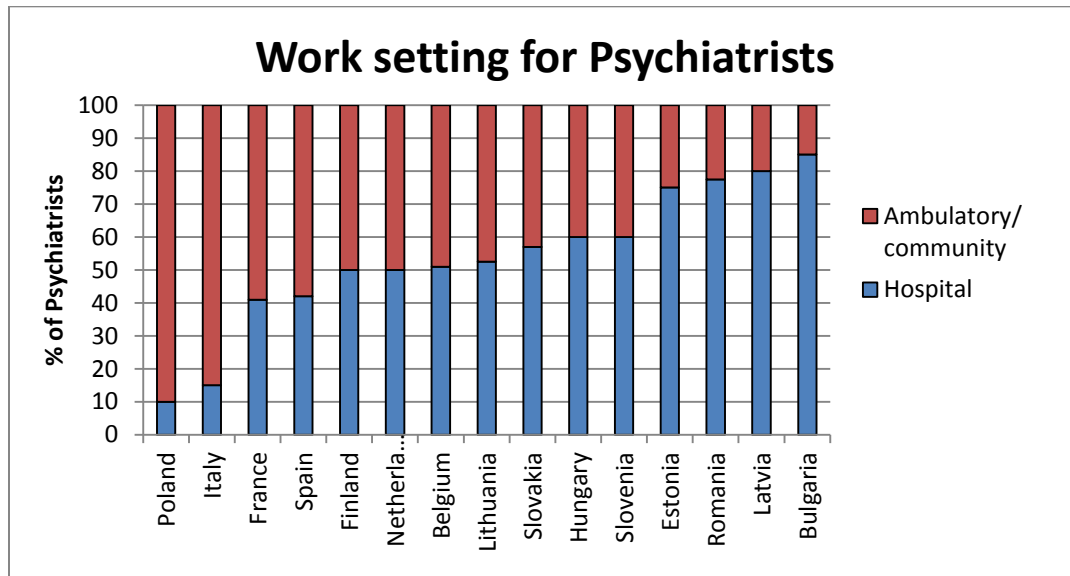
Variations in responses:

- Figures for one setting
- Figures for both settings
- Approximate figures
- The number of professionals in the different settings

Following the pattern of the previous two questions, Poland has the lowest % for professionals working in a hospital setting, although for psychiatrists it is a lot

lower than for other professionals. Overall, most countries indicate that the majority of psychiatrists work in a hospital setting.

Figure 18: Work setting for Psychiatrists



### What percentage of Old Age Psychiatrists work in hospital or ambulatory/community settings?

Number of responses: 8/9

- The question was not applicable for Italy as it has no Old Age Psychiatrists

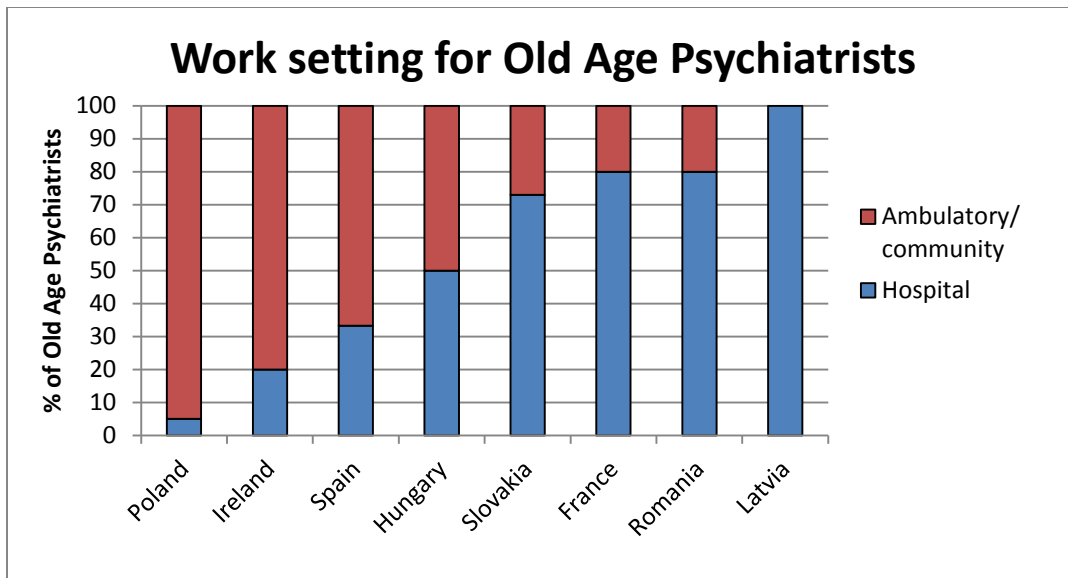
Number of missing responses: 15 – this question was only added in the new version of the questionnaire, so people completing the original version would not have answered it.

Variations in responses:

- Figures for one setting
- Figures for both settings
- Approximate figures
- The number of professionals in the different settings

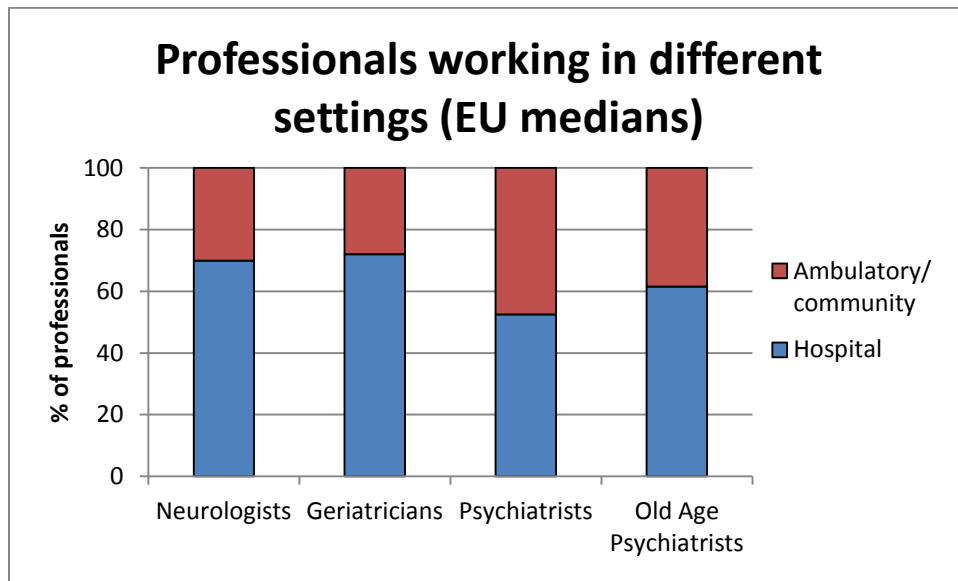
As can be seen in Figure 19, the situation in Poland is almost opposite to the one in Latvia, with nearly all old age psychiatrists working in an ambulatory setting in Poland, compared to all working in hospitals in Latvia. Overall though, it appears that most old age psychiatrists work in a hospital setting across the EU.

Figure 19: Work setting for Old Age Psychiatrists



The median values for each profession were calculated and used as the EU averages. These are shown in Figure 20 and indicate that across all professions, most people work in a hospital setting.

Figure 204: Work setting for professionals across the EU based on median values



### What is the average stage of dementia at the moment of diagnosis?

Number of responses: 20/23

- Netherlands and Luxembourg said that no data was available
- Estonia gave the number of cases diagnosed

Number of missing responses: 1

- This question was left blank by Bulgaria

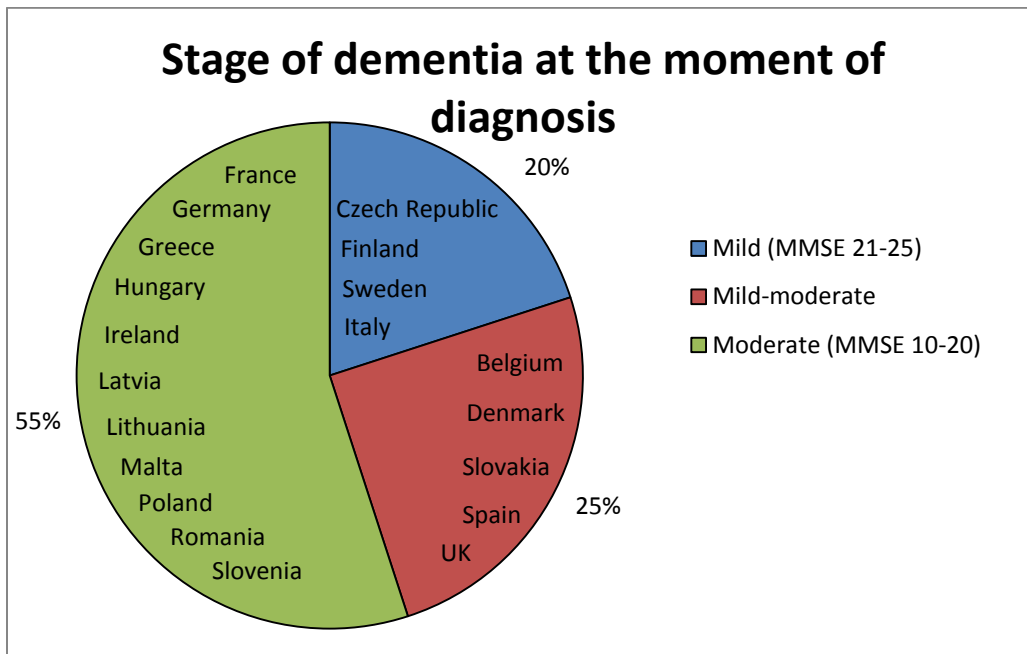
Variations in responses:

- Mini-Mental State Examination (MMSE) score(s)
- Description

It can be seen from Figure 21

that in most countries dementia is diagnosed when it is at a moderate stage, with only four countries claiming to diagnose it when it is still mild.

Figure 21: Average stage of dementia at the moment of diagnosis

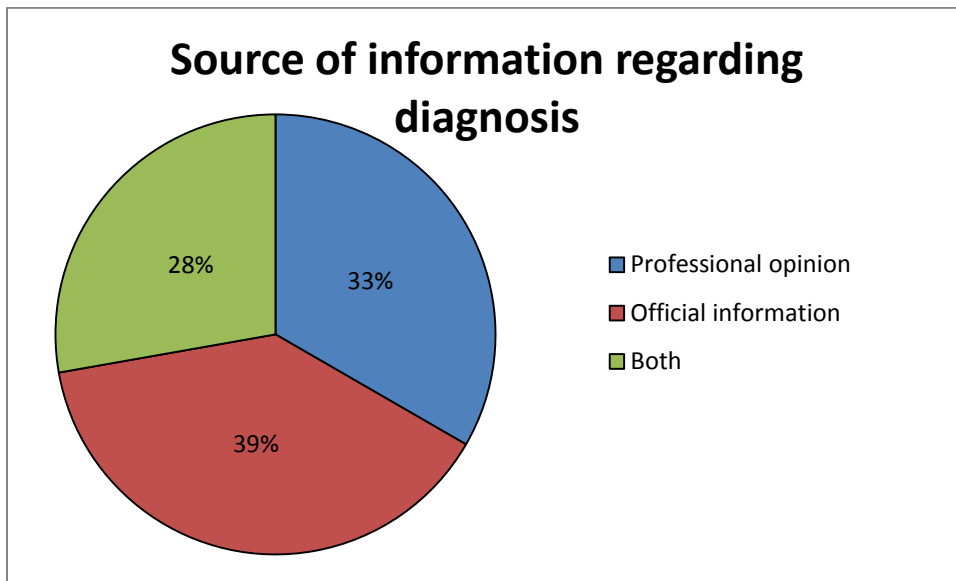


In terms of the source of the information regarding diagnosis, Figure 22 indicates that there is a fairly even split between professional opinion and official information, with a number of countries using both sources. It is not known why professional opinion was used so often, although one country did comment that their response was based on “personal experience as no data is available”.

Examples of the official information used include:

- National Health Service
- Memory Centre Database/National Alzheimer Database
- Health Insurance (mentioned by three countries)
- Dementia Registry
- Surveys and studies

Figure 22: Source of diagnosis information



### What percentage of diagnoses are missed?

Number of responses: 16/23

- Netherlands, Ireland, Malta, Belgium and Luxembourg said that data was unknown or not available
- Sweden gave the response N/A
- It was not possible to derive a value from the response given by Lithuania

Number of missing responses: 1

- This question was left blank by Bulgaria

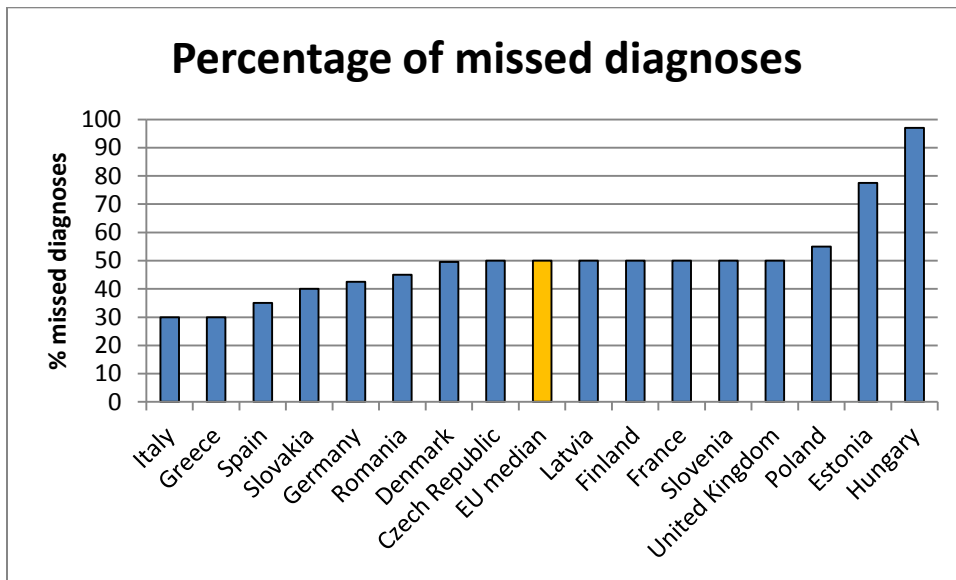
Variations in responses:

- Approximate values
- Precise values
- Ranges
- The percentage receiving a diagnosis

The responses shown in Figure 23 indicate the variation between countries. Even ignoring the responses at either extreme, the situation across the EU is not promising with 40-60% of diagnoses being missed by most countries.

- Response verification for Hungary – only limited information was found on the Internet and did not contradict the high response given for Hungary.

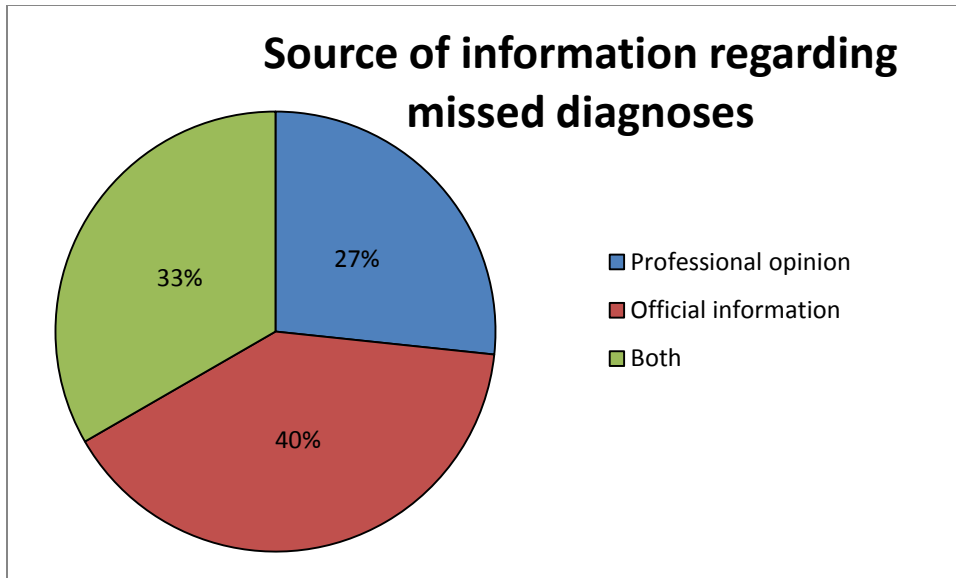
Figure 235: % missed diagnoses



In terms of where the information was obtained, professional opinion was slightly less likely to be used than official information. Examples of the official information used include:

- Health insurance
- Surveys and studies
- Alzheimer's Societies

Figure 246: Source of information about missed diagnoses



## Diagnosis

### Does your country have national official guidelines for diagnosis?

Number of responses: 23

- Latvia and Denmark both gave multiple responses which were conflicting, and so were classed as 'Unclear'

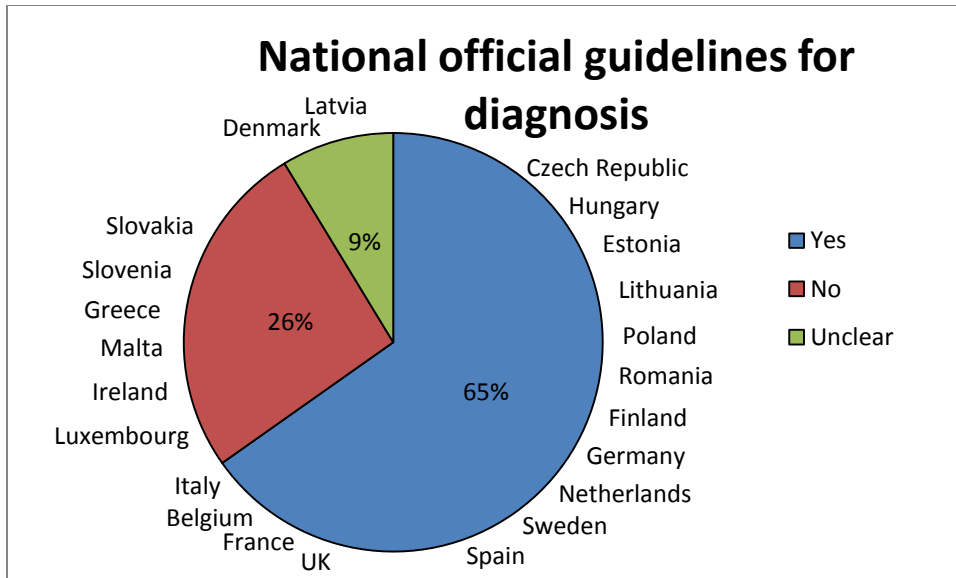
Number of missing responses: 1

- This question was left blank by Bulgaria

Nearly two-thirds of countries reported having national official guidelines for diagnosis in place, and although this is promising it indicates that there is room for improvement.

*Figure 25: Countries with/without national official guidelines for diagnosis*

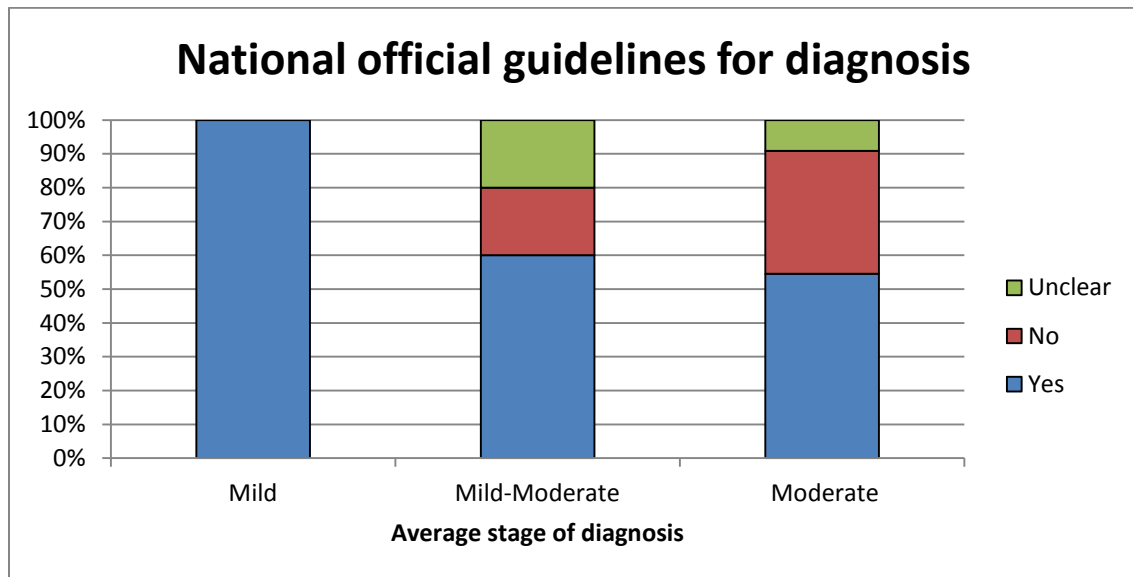




In terms of the website links provided for the guidelines, many were not in English so it was difficult to find out much about them. For some countries the website link did give some indication of which organisations were involved, and they tended to be Alzheimer’s Societies and National Health Organisations.

Based on the responses given for a previous question about the average stage at which a dementia diagnosis is made, Figure 26 groups together countries which diagnose at the same stage. From this it can be seen that all of the countries diagnosing at mild stage have national official guidelines in place, while countries diagnosing at moderate stage are least likely to have such guidelines. This suggests that having national guidelines for diagnosis could have an impact in terms of bringing forward the point at which a dementia diagnosis is made.

Figure 26: National official guidelines for diagnosis split by average stage of diagnosis



### Which tools are most frequently used in day-to-day practice to detect early dementia?

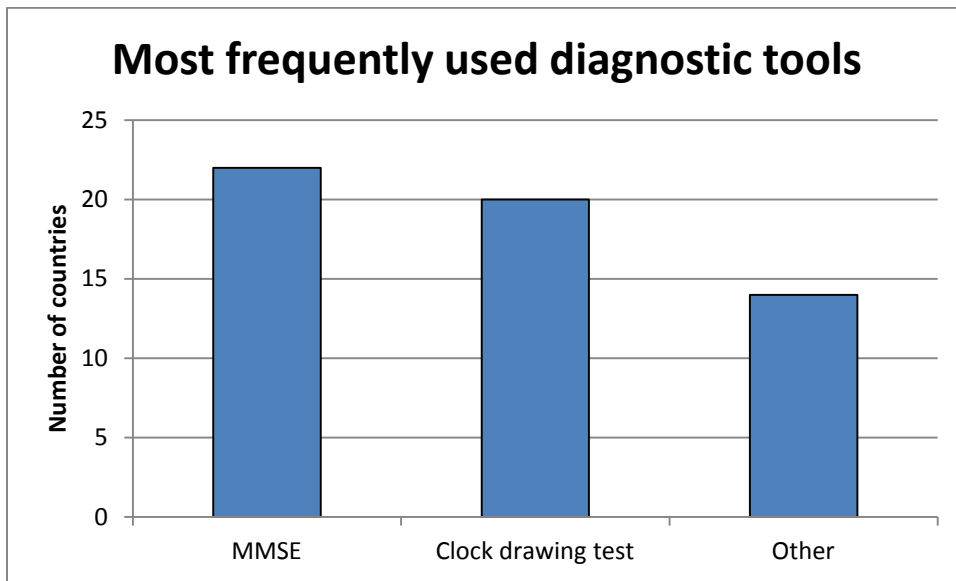
Number of responses: 23

Number of missing responses: 1

- This question was left blank by Bulgaria

The most common tools are MMSE and the clock drawing test, which are consistently used across Europe – every country that responded used at least one of these two tools. A variety of other tools were mentioned but were not really common, especially in terms of being ‘most frequently used’. In general, most of the ‘other’ tools were only mentioned by one country, and included: the Montreal Cognitive Assessment (MoCA), Addenbrooke’s Cognitive Examination – Revised (ACE-R), Alzheimer’s Disease Assessment Scale – Cognition (ADAS-Cog), Cambridge Cognition Examination (CAMCOG), Consortium to Establish a Registry for Alzheimer’s Disease (CERAD), Dementia Toolkit for Effective Communication (DemTEC), Milan Overall Dementia Assessment (MODA) and Mental Deterioration Battery (MDB).

Figure 27: Diagnostic tools most frequently used to detect early dementia



### Do you have allied medical professionals to test memory?

Number of responses: 22/23

- Lithuania was the only country to respond 'No'

Number of missing responses: 1

- This question was left blank by Bulgaria

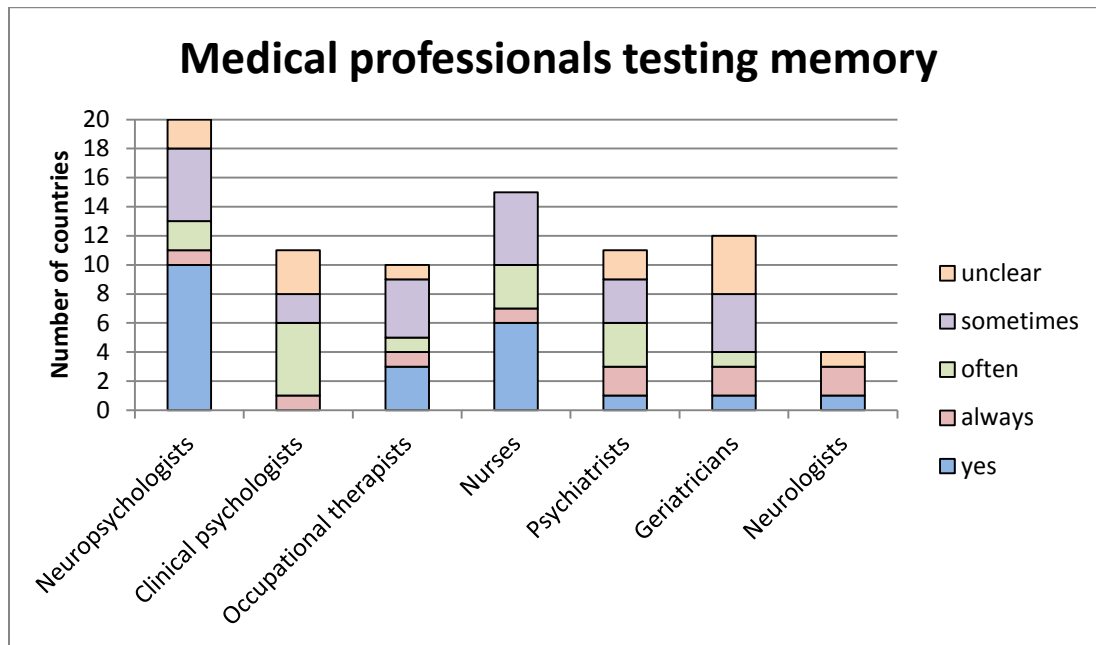
Variations in responses:

- List of professionals
- Professionals and how often they are used

Where multiple responses were given for a country, two approaches were taken. If the responses agreed on a profession but not the frequency, the lesser frequency was used (e.g. sometimes would be used if both often and sometimes were given). If the responses did not agree on a profession it is marked as unclear.

As can be seen from Figure 28 memory tests were most likely to be carried out by Neuropsychologists, followed by Nurses, with Neurologists the least likely profession. The only two countries who do not use Neuropsychologists to test memory are Slovenia and Malta.

Figure 28: Medical professionals testing memory in different countries



The responses for this question have been separated based on the stage at which a dementia diagnosis is made in different countries, and are shown in Figure 29, Figure 30 and Figure 31. From these graphs, it can be seen that regardless of the stage of diagnosis, Neuropsychologists and Nurses are likely to be involved in testing memory. Occupational Therapists are more likely to be involved in countries who diagnose at mild stage, while Geriatricians are less likely to be involved. Countries who diagnose at Moderate stage are more likely to involve Psychiatrists. These responses indicate that the role of professionals in performing memory tests can differ depending on how early a dementia diagnosis is made, or conversely, the stage at which a diagnosis is made can depend on which professionals are involved.

Figure 29: Medical professionals testing memory in countries diagnosing at mild stage

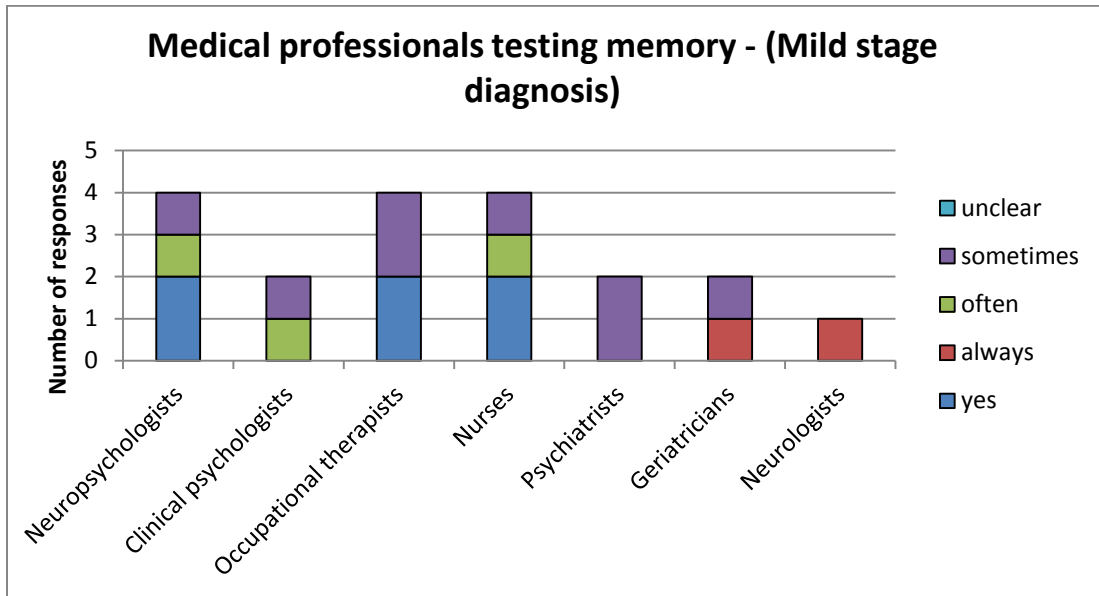


Figure 30: Medical professionals testing memory in countries diagnosing at mild-moderate stage

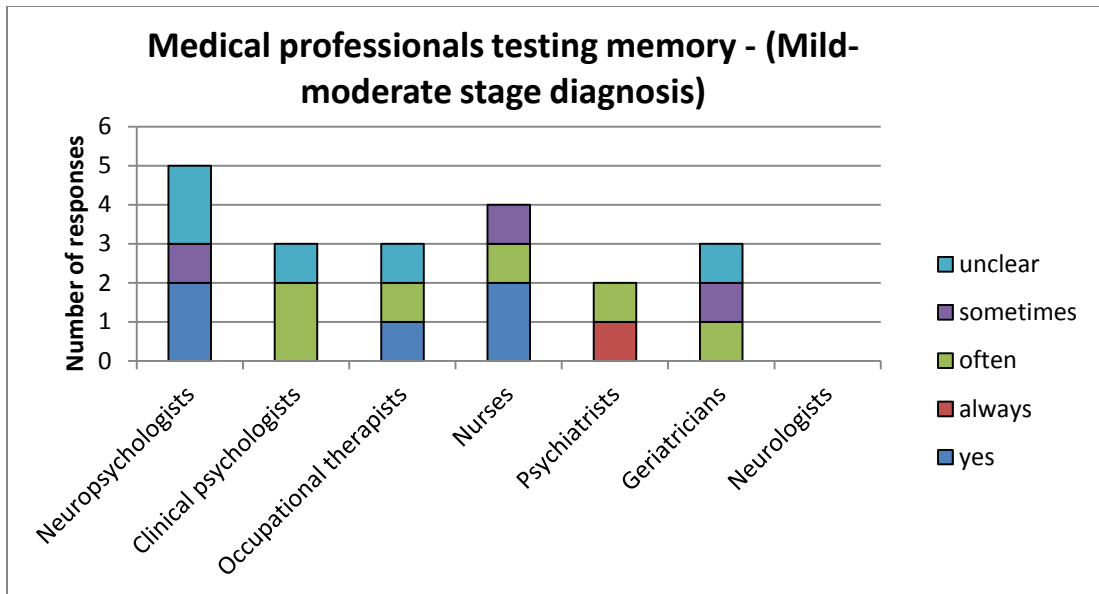
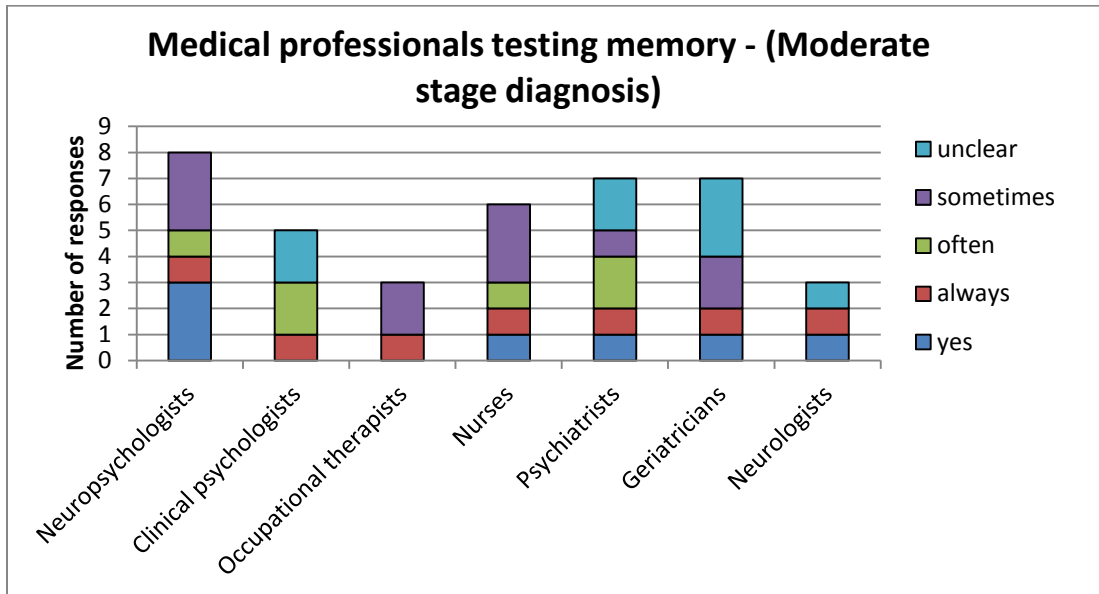


Figure 317: Medical professionals testing memory in countries diagnosing at moderate stage



### How many of each kind of professional are there?

Number of responses: 18

- Germany and Luxembourg responded 'Not known' or 'Data not available'
- Sweden said 'n/a'

Number of missing responses: 6

- This question was left blank by Bulgaria, Czech Republic, Lithuania, Malta, Belgium and Ireland

Variations in responses:

- Specific numbers
- Approximate numbers
- Ranges
- National information
- Local information
- Responses for all professions
- Responses for some professions

Unfortunately, the information for this question was very inconsistent, with some countries giving answers at a national level, others responding at a local level, and others not being clear about the level of their responses. There was also limited

information for each of the different professions. Consequently, no useful results could be obtained for this question.

**Do you have screening services for dementia and/or mild cognitive impairment?**

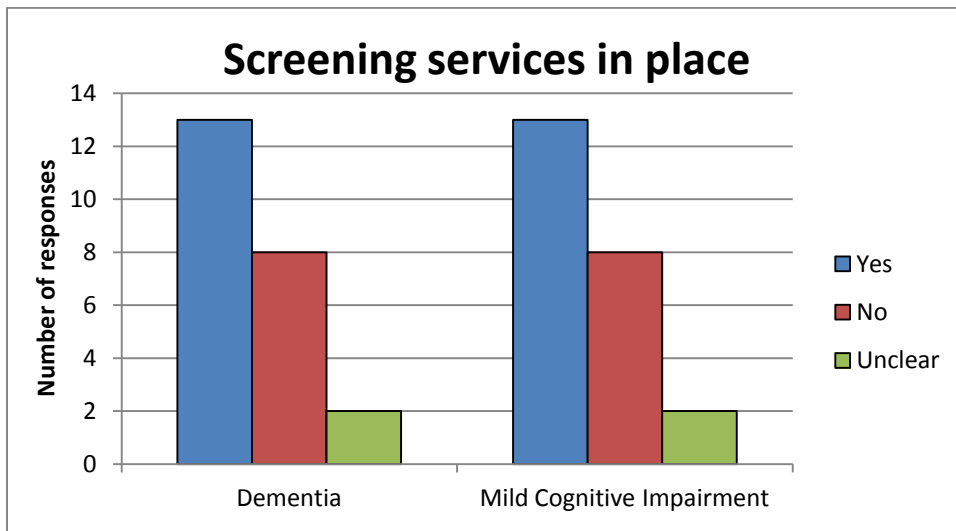
Number of responses: 23

Number of missing responses: 1

- This question was left blank by Bulgaria

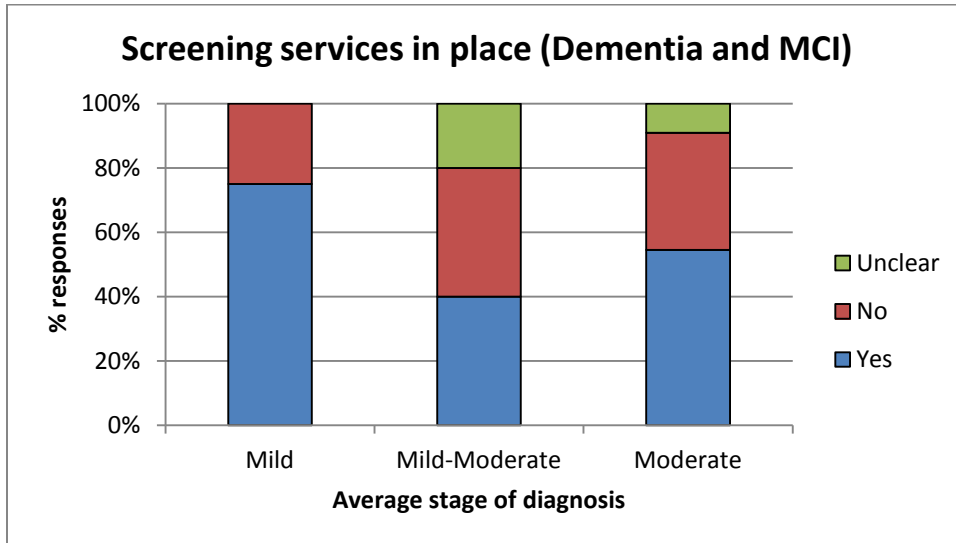
In the updated version of the questionnaire this question was split into two, looking at dementia separately from mild cognitive impairment (MCI). If a country completed the original questionnaire, their response was assumed to be the same for both conditions, i.e. 'Yes' meant yes for dementia screening and yes for MCI screening. This assumption appears to be reasonable, as the responses for countries who answered the new version of the questionnaire were actually the same for both dementia and MCI. The eight countries without screening services are Hungary, Estonia, Lithuania, Germany, Sweden, Denmark, Malta and United Kingdom.

Figure 32: Screening services in place for dementia and mild cognitive impairment



By considering the responses based on the average stage at which a dementia diagnosis is made, it can be seen (Figure 33) that countries which diagnose at mild stage are most likely to have screening services in place. The pattern for the other stages of diagnosis is less apparent, due to the number of 'Unclear' responses.

Figure 33: Screening services in place based on average stage of diagnosis



### Where are the screening services located?

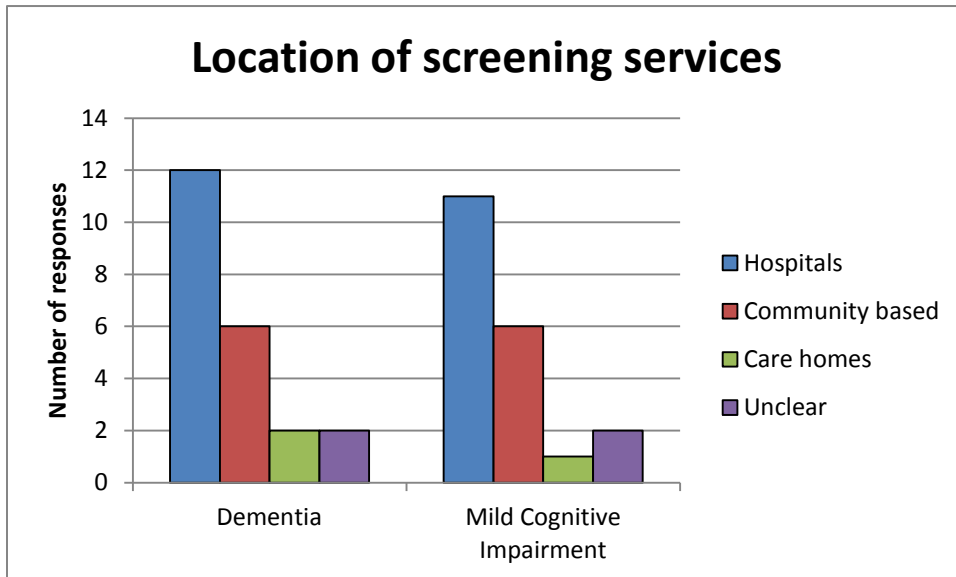
Only the responses from the countries with screening services were considered.

Number of responses: 15



From Figure 34 it can be seen that the responses for dementia and MCI were almost identical, with both most likely to be located in hospitals. Screening services were least likely to be found in care homes.

Figure 34: Location of screening services for dementia and mild cognitive impairment



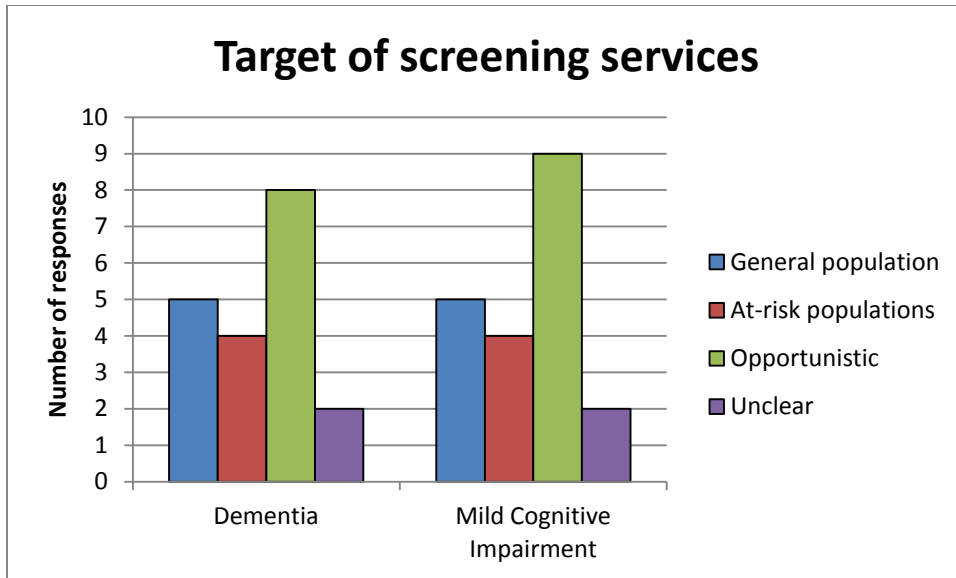
### What are the screening services for?

Only the responses from the countries with screening services were considered.

Number of responses: 14

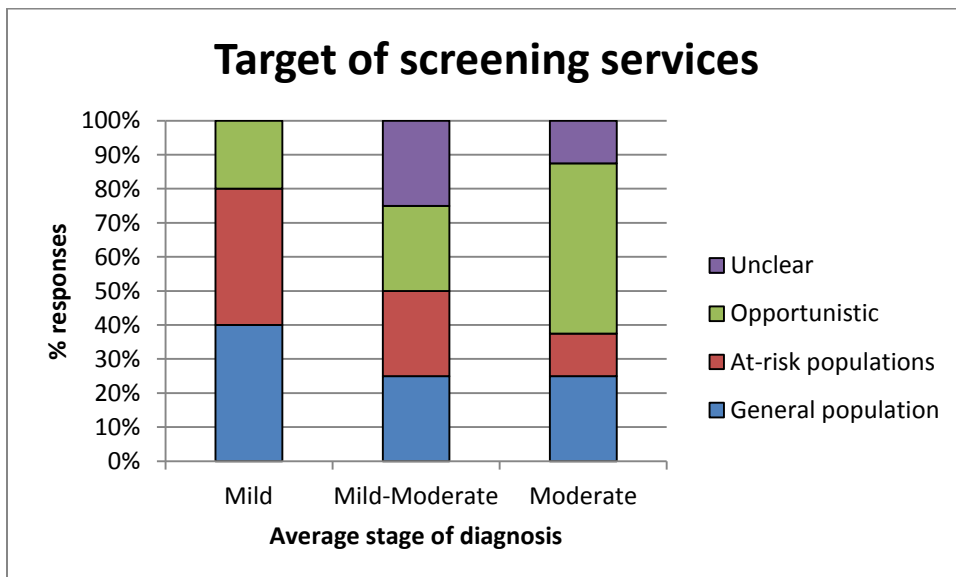
As with the location of the screening services, the responses regarding the target populations are almost identical for dementia and MCI. It can be seen from Figure 35 that most screening is opportunistic, which is not overly surprising if most screening is taking place in hospitals rather than actively targeting different groups in different locations. There is however the question of what people understand by screening, as opportunistic screening in hospitals sounds more like testing people who may already be experiencing difficulties.

Figure 35: Target population of screening services for dementia and mild cognitive impairment



From Figure 36 it can be seen that countries diagnosing dementia at mild stage are more likely to target their screening services at either general or at-risk populations, while countries diagnosing at moderate stage are most likely to carry out opportunistic screening. This indicates that taking a more systematic approach to screening can potentially have an impact on the stage at which a diagnosis is made.

Figure 36: Target population of screening services based on average stage of diagnosis



## Theory vs. practice

### **Regarding medical imaging, what is recommended for young/working age patients and what is actually implemented?**

Number of responses: 23

Number of missing responses: 1

- This question was left blank by Bulgaria

As can be seen from Figure 37 the medical imaging that is actually implemented for young/working age people is quite similar to the recommendations. Overall, 18 of 23 countries (78%) implement the same types of medical images as their recommendations suggest. Three countries implement fewer types of medical images, and two countries implement more. The 'Other' types of medical imaging used are Cerebrospinal Fluid (CSF), Fluorodeoxyglucose Positron Emission Tomography (FDG PET) and FP-CIT (DaT scan)<sup>3</sup>. Where imaging is used for specific patients, these include patients with:

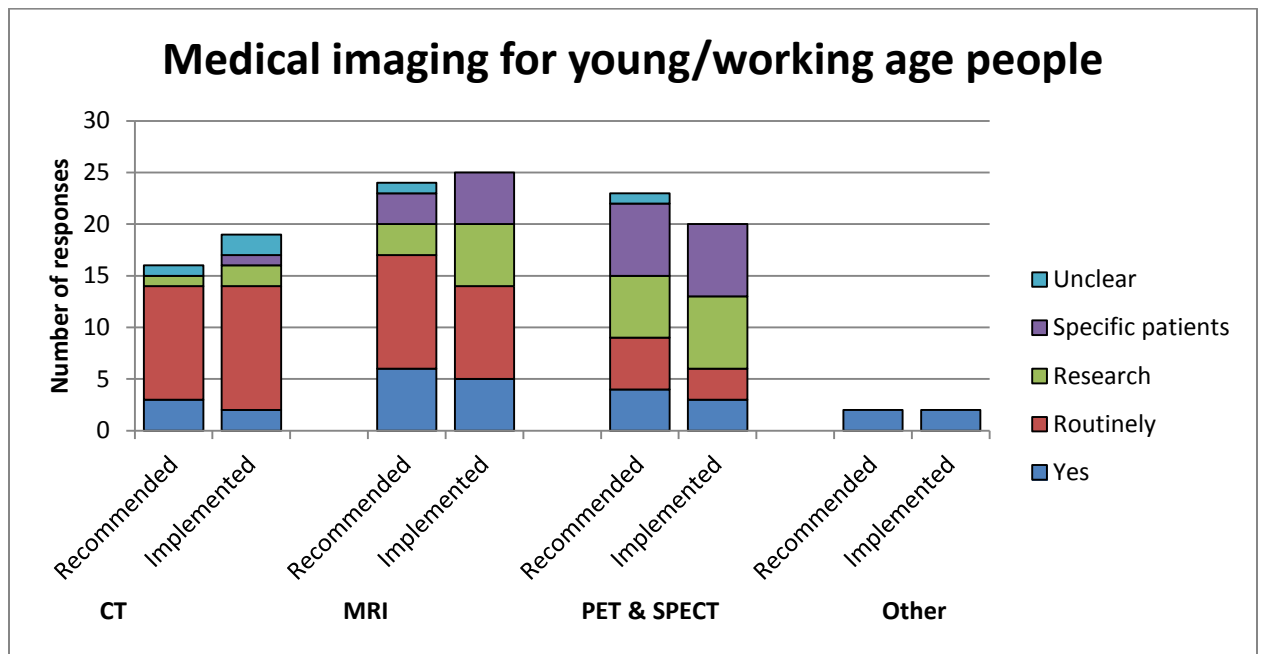
- Atypical symptoms
- Frontotemporal dementia
- High hereditary risk
- Need for differential diagnosis

From the responses it can be seen that Computed Tomography (CT) and Magnetic Resonance Imaging (MRI) scans are used much more routinely, while PET & Single-Photon Emission CT (SPECT) is used more for research purposes of for specific patients.

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<sup>3</sup> I-Fluoropropyl-2-beta-carbomethoxy-3-beta(4-iodopyrenyl) nortropane (FP-CIT) Dopamine Transporter (DaT)

Figure 37: Medical imaging that is recommended and actually implemented for young/working age people



### Regarding medical imaging, what is recommended for pre-dementia/MCI and what is actually implemented?

Number of responses: 23

Number of missing responses: 1

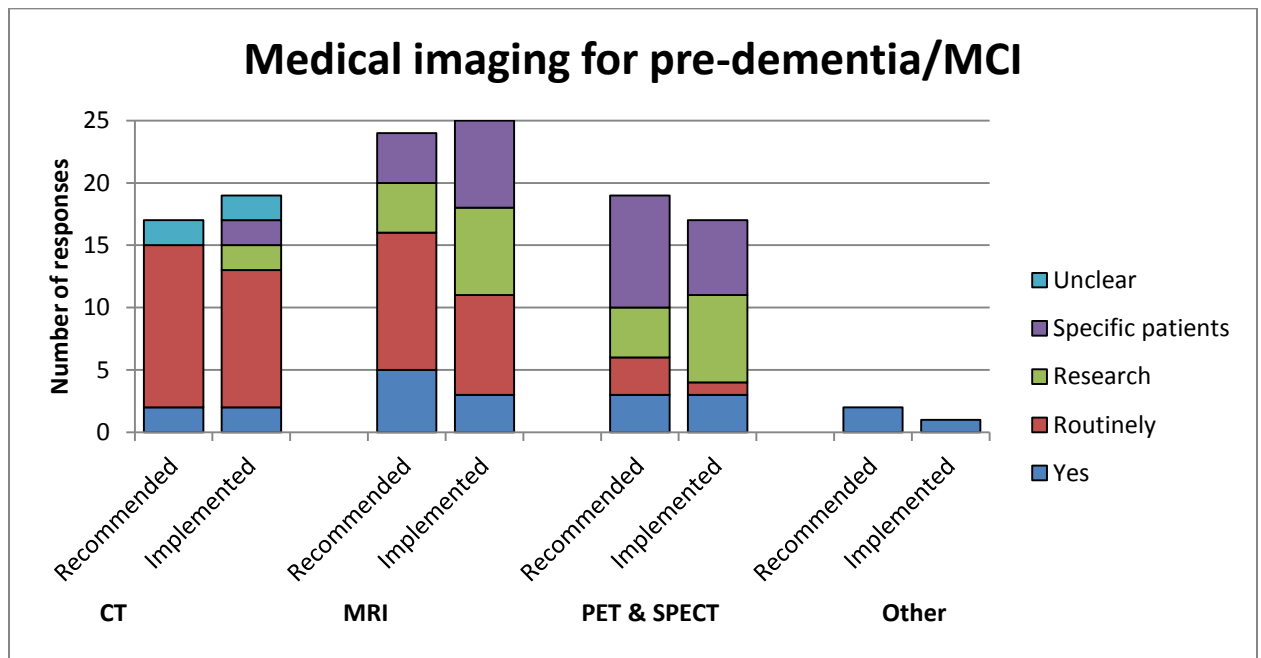
- This question was left blank by Bulgaria

The recommended and implemented medical images are again quite similar, although all types are used less routinely and more for research and for specific patients than the recommendations indicate. 15 countries (65%) use the same types of imaging as recommended, while four implement fewer types and four implement more types than their recommendations. It is generally the PET & SPECT which is included or omitted. The 'Other' types of medical imaging used were again CSF, FDG PET and FP-CIT (DaT scan). Where imaging is used for specific patients, these include patients with:

- Atypical symptoms
- Frontotemporal dementia
- High hereditary risk/family history
- Need for differential diagnosis

- Apolipoprotein E4 (APOE4) positive

Figure 38: Medical imaging that is recommended and actually implemented for pre-dementia/MCI



### Regarding medical imaging, what is recommended for early patients without obvious clinical signs and what is actually implemented?

Number of responses: 22

Number of missing responses: 2

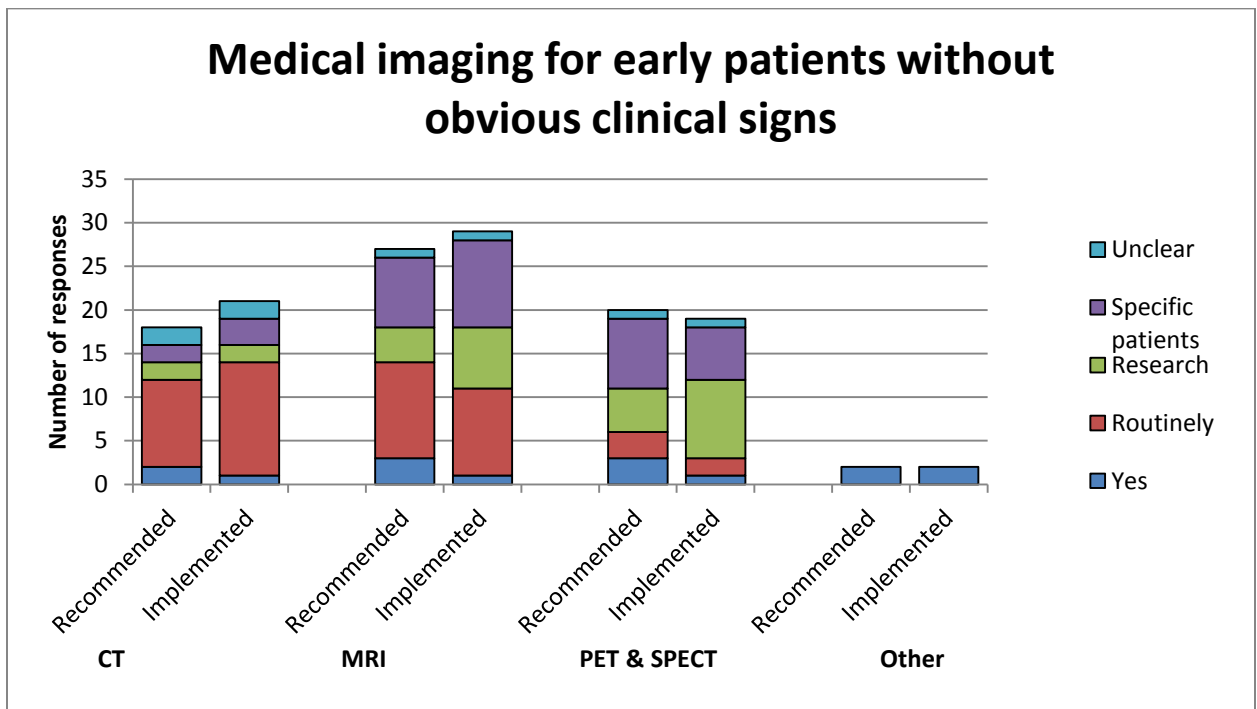
- This question was left blank by Bulgaria and Ireland

As seen in Figure 39, CT scans were most likely to be used routinely, MRI scans were used routinely and for specific patients, and PET & SPECT imaging was more for specific patients, although the latter two were used more for research than the recommendations suggested. 11 countries (50%) use the same types of imaging as recommended, while three implement fewer types and eight implement more types than their recommendations. As for the previous question, PET & SPECT was the most likely to be included or omitted. The 'Other' types of medical imaging used were FDG PET and FP-CIT (DaT scan). Where imaging is used for specific patients, these include patients with:

- Atypical symptoms
- High hereditary risk/family history
- Frontotemporal dementia

- Need for differential diagnosis

Figure 39: Medical imaging that is recommended and actually implemented for early patients without obvious clinical signs



### Regarding medical imaging, what is recommended for early patients with obvious clinical signs and what is actually implemented?

#### *Response information for recommendations*

Number of responses: 23

Number of missing responses: 1

- This question was left blank by Bulgaria

#### *Response information for implementation*

Number of responses: 22

Number of missing responses: 2

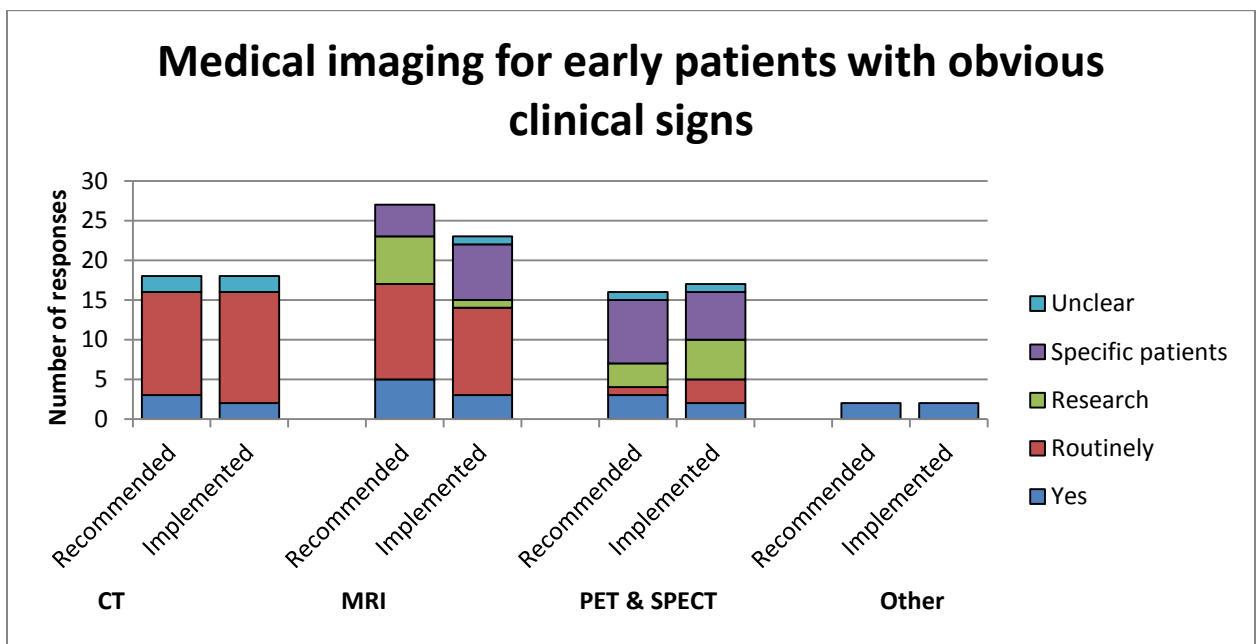
- This question was left blank by Bulgaria and Ireland

CT and MRI scans are used routinely, while PET & SPECT are used most for specific patients. In terms of implementation, MRI are used more for specific patients and less for research than recommended, and PET & SPECT is the opposite. 14 countries (64%) use the same types of imaging as recommended, while four

implement fewer types and three implement more types than their recommendations. One country (Greece) is different as it does not implement CT but does implement PET & SPECT, both of which go against the recommendations. The 'Other' types of medical imaging used were again FDG PET and FP-CIT (DaT scan). Where imaging is used for specific patients, these include patients with:

- Atypical symptoms
- Frontotemporal dementia
- Need for a differential diagnosis

Figure 40: Medical imaging that is recommended and actually implemented for early patients with obvious clinical signs



### Regarding medical imaging, what is recommended for late stage and what is actually implemented?

Number of responses: 23

Number of missing responses: 1

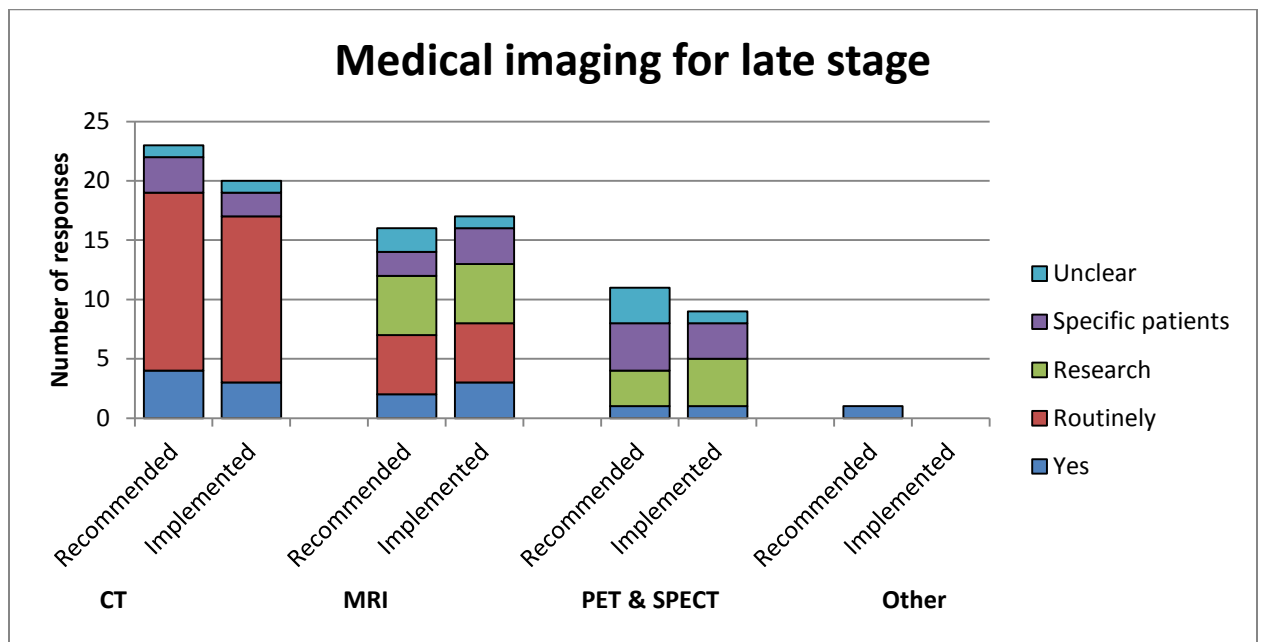
- This question was left blank by Bulgaria

It is noticeable from Figure 41 that the medical imaging for late stage dementia follows a different pattern than for the other stages. CT scans are the most common type of imaging, and are used routinely. MRI and PET & SPECT are used less often, and are most likely to be for research purposes, with MRI only being used routinely by a few countries. 12 countries (52%) use the same types of

imaging as recommended, while seven implement fewer types and four implement more types than their recommendations. The 'Other' types of medical imaging used were again FDG PET and FP-CIT (DaT scan). Where imaging is used for specific patients, it includes patients with:

- Atypical symptoms
- Need for a differential diagnosis
- Frontotemporal dementia

Figure 418: Medical imaging that is recommended and actually implemented for late stage



### Are the practices recommended across all regions in your country?

Number of responses: 22/23

- The response for Romania was unclear

Number of missing responses: 1

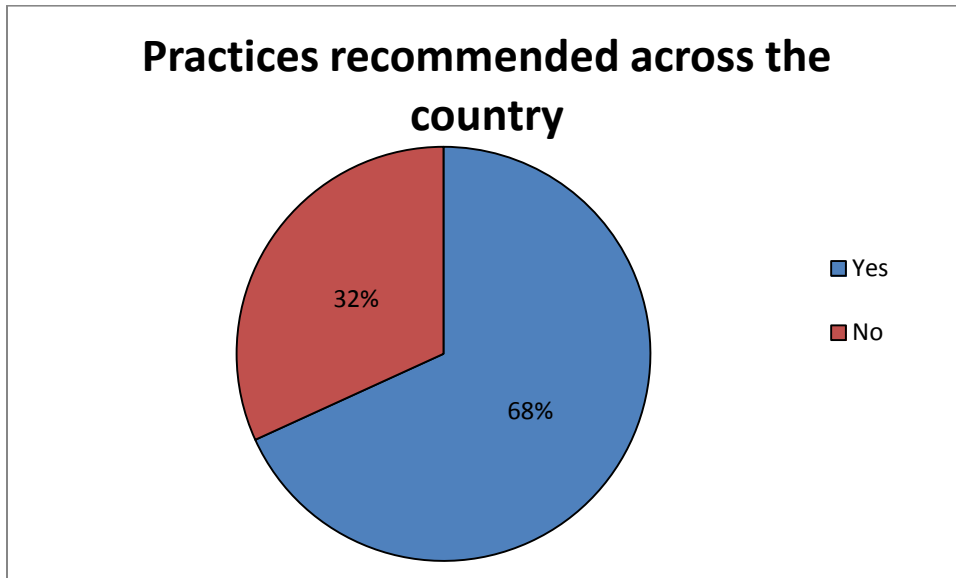
- This question was left blank by Bulgaria

From Figure 42 it can be seen that in most countries the types of medical imaging from the previous questions are recommended across all regions. For the countries responding 'No', comments were made to say that:

- There are variations due to resources and availability
- There are no national guidelines



Figure 42: Whether practices are recommended across all regions in a country



### What evidence were the medical imaging practices based on?

Number of responses: 16/21

- The responses for Malta and Belgium were unclear
- Estonia and Denmark did not understand the question (the original wording of the question was different, and caused confusion)
- Luxembourg said that no data was available

Number of missing responses: 3

- This question was left blank by Bulgaria, Lithuania and Finland

### ***Response information for implemented medical imaging***

Number of responses: 12

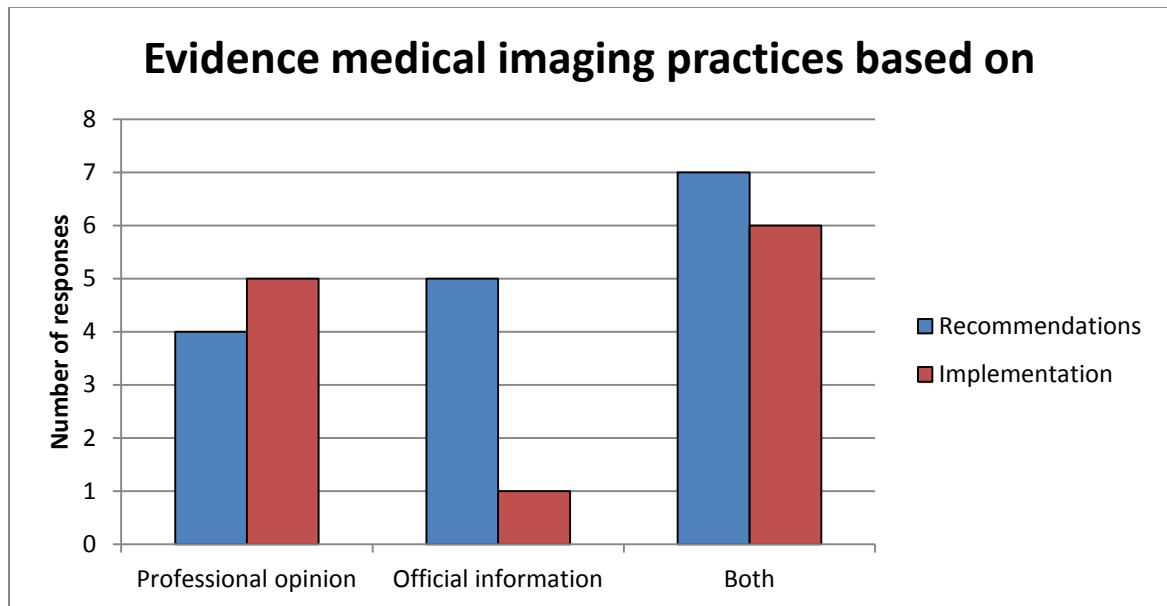
Number of missing responses: 12

This question was added in to the new version of the questionnaire and so was not answered by any country filling in the original version. Overall, this question was not answered by: Bulgaria, Estonia, Lithuania, Finland, Netherlands, Germany, Sweden, Denmark, Greece, Malta, Belgium and Luxembourg.

The responses shown in Figure 43 indicate that the recommendations and implementation are most likely to be based on both professional opinion and

official information, and the actual medical imaging implemented is least likely to be based just on official information.

Figure 43: What evidence the medical imaging practices were based on



### In your country are biomarkers measured in the cerebrospinal fluid?

Number of responses: 21/23

- The responses for Romania and Germany were unclear

Number of missing responses: 1

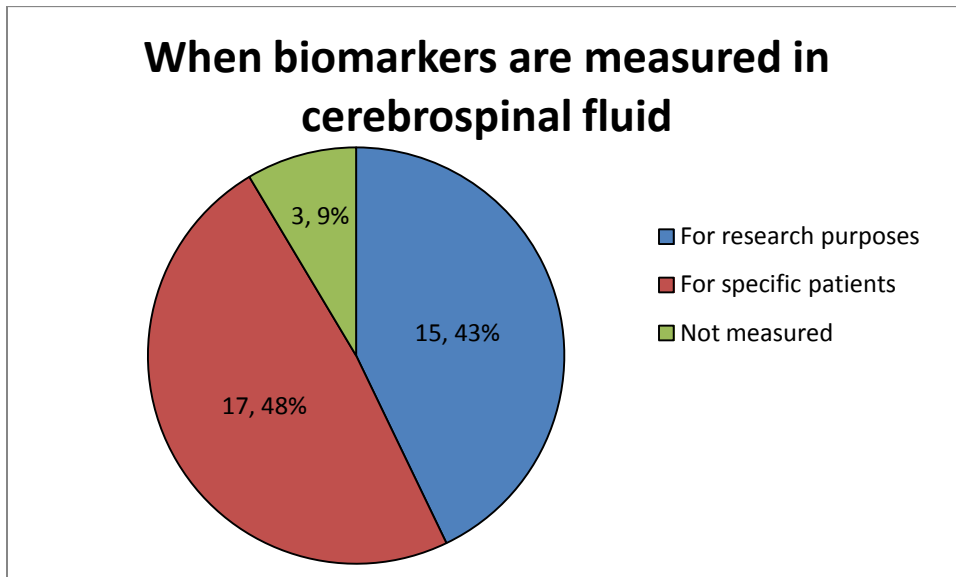
- This question was left blank by Bulgaria

Only three countries (Estonia, Latvia and Malta) do not measure biomarkers in cerebrospinal fluid. Of the other 17 countries, 14 (82%) measure biomarkers for both research purposes and specific patients. In terms of who the specific patients are, responses included:

- Young/early onset
- Atypical presentations
- Family history
- Unsettled/unclear diagnosis
- Older than 65

- Rapidly progressive dementia
- Pre-dementia/MC

Figure 449: When biomarkers are measured in cerebrospinal fluid



**Who are officially designated to assess intellectual functions including a memory test, and who actually does in day-to-day practice?**

***Response information for official designation***

Number of responses: 21/23

- The responses for Slovakia and Sweden were unclear

Number of missing responses: 1

- This question was left blank by Bulgaria

***Response information for day-to-day practice***

Number of responses: 22

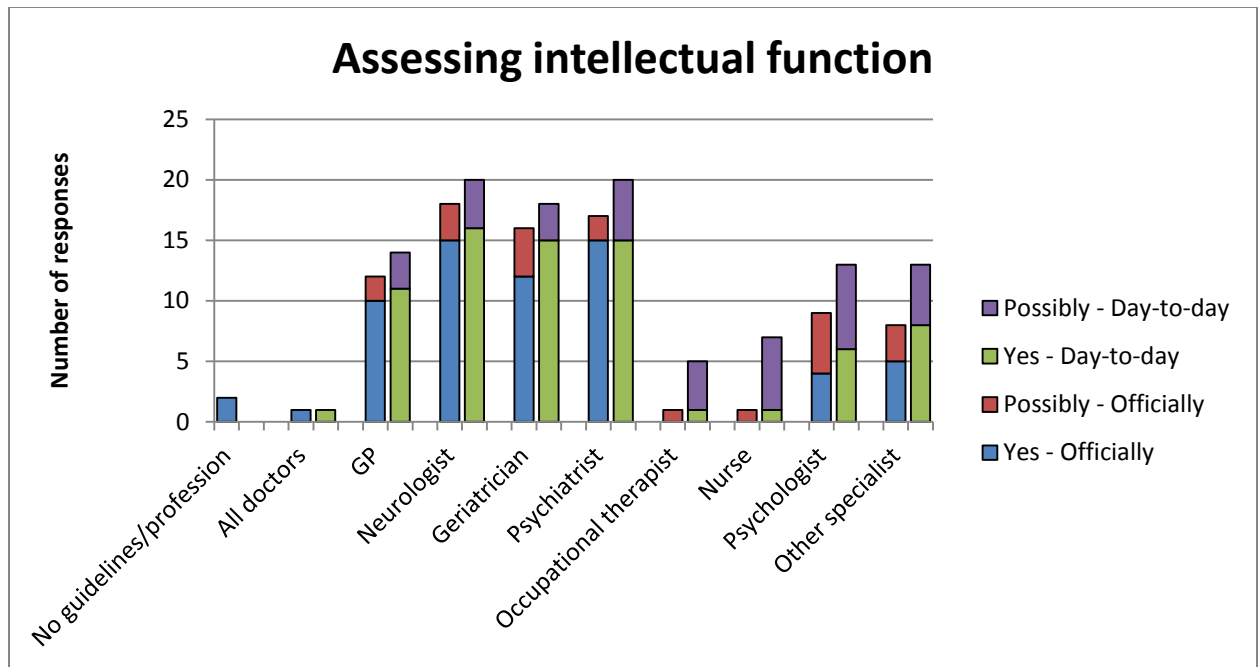
Number of missing responses: 2

- This question was left blank by Bulgaria and Belgium

Figure 45 indicates that there are four main professions carrying out this role: GP, Neurologist, Geriatrician and Psychiatrist. The responses also indicate that there is some difference between what is official and what actually takes place, with all

professions more likely to carry out the role in day-to-day practice. The other specialists mentioned were generally neuropsychologists. Latvia and Ireland said that they had no guidelines in place, while Malta said that this role could be carried out by all doctors.

Figure 45: Assessing intellectual function including a memory test



## Who are officially designated to make a diagnosis overall, and who actually does in day-to-day practice?

### *Response information for official designation*

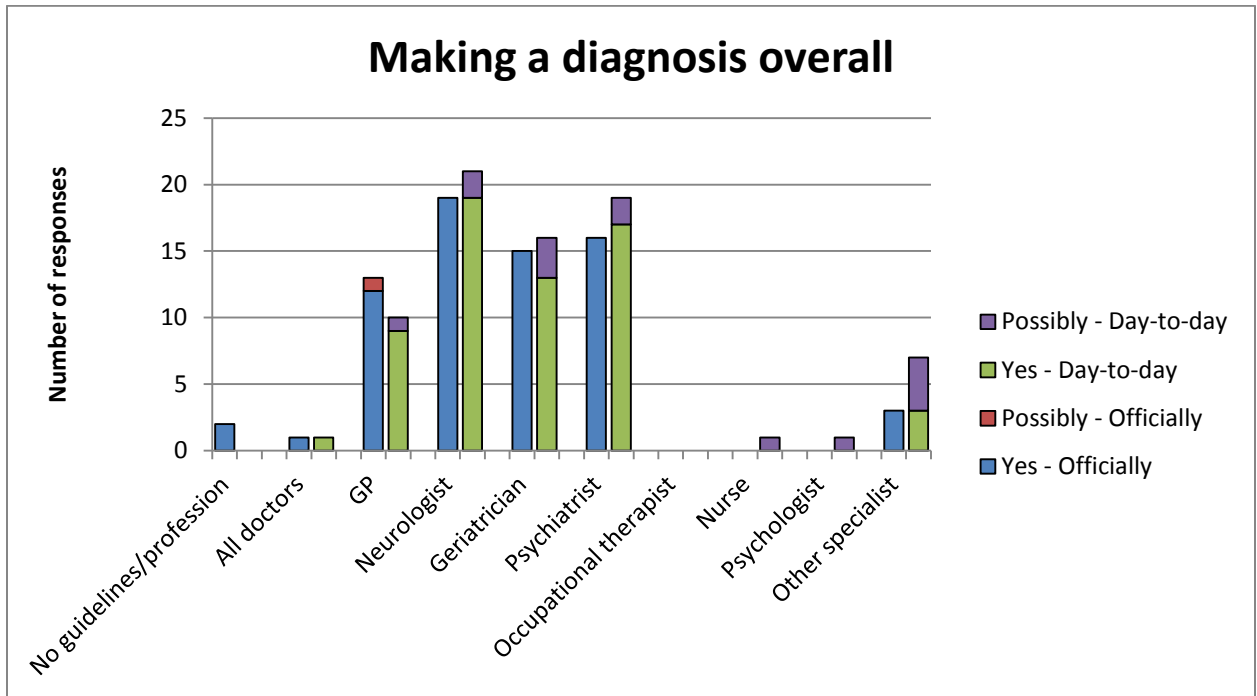
Number of responses: 23

Number of missing responses: 1

- This question was left blank by Bulgaria

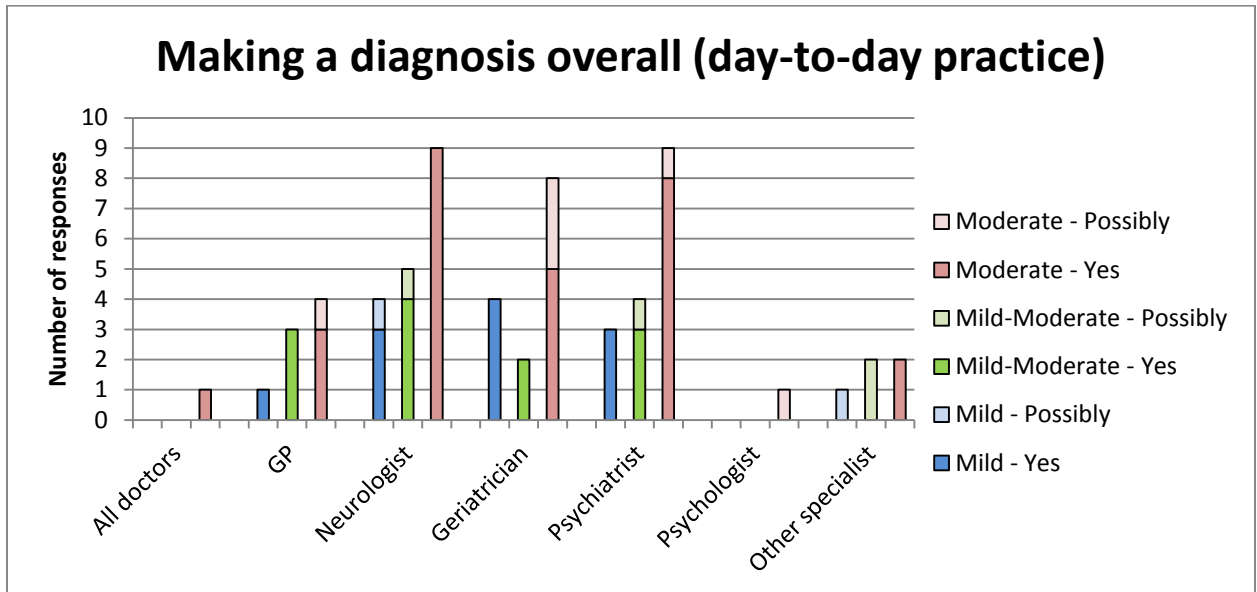
The main four professions are again GP, Neurologist, Geriatrician and Psychiatrist. The responses for what actually takes place are very similar to what is officially recommended. Again, Latvia and Ireland said that they had no guidelines in place, while Malta said that this role could be carried out by all doctors.

Figure 46: Making a diagnosis overall



The responses for the day-to-day practice in different countries are considered separately based on the average stage at which countries make a dementia diagnosis. As can be seen in Figure 47, countries who diagnose at mild-moderate stage are possibly less likely to use Geriatricians to make an overall diagnosis, but more likely to use GPs. Overall, Neurologists, Geriatricians and Psychiatrists were the main professions involved regardless of diagnosis stage.

Figure 47: Making a diagnosis overall in day-to-day practice based on average stage of diagnosis



**Who are officially designated to make a diagnosis in simple cases, and who actually does in day-to-day practice?**

Number of responses: 20/21

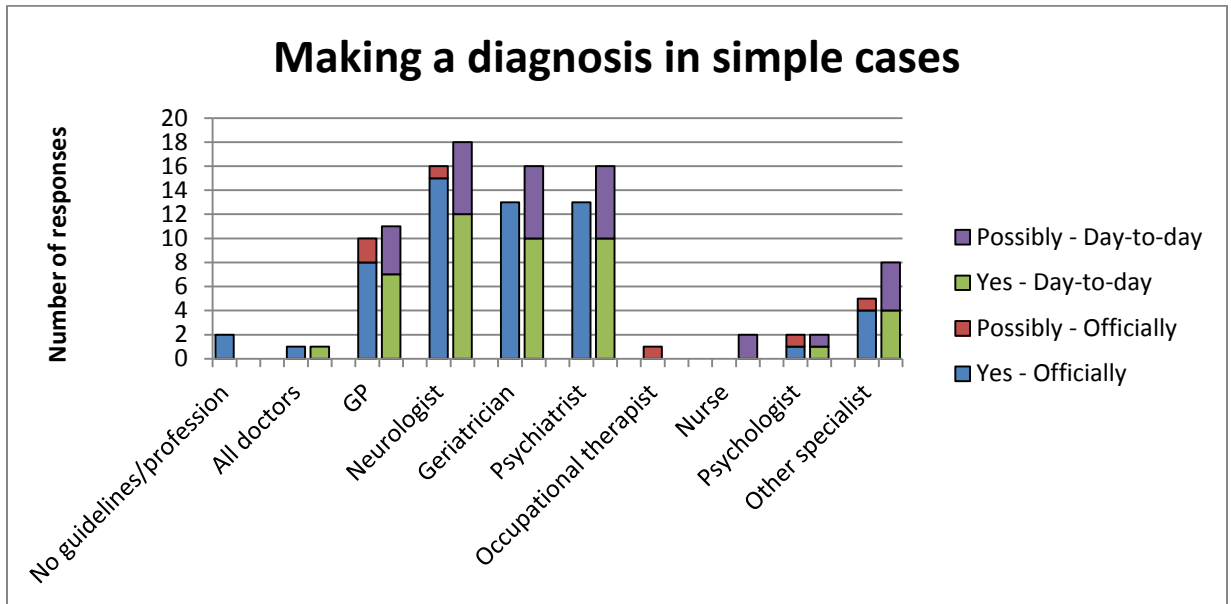
- Greece responded that this was not applicable

Number of missing responses: 3

- This question was left blank by Bulgaria, Lithuania and Belgium

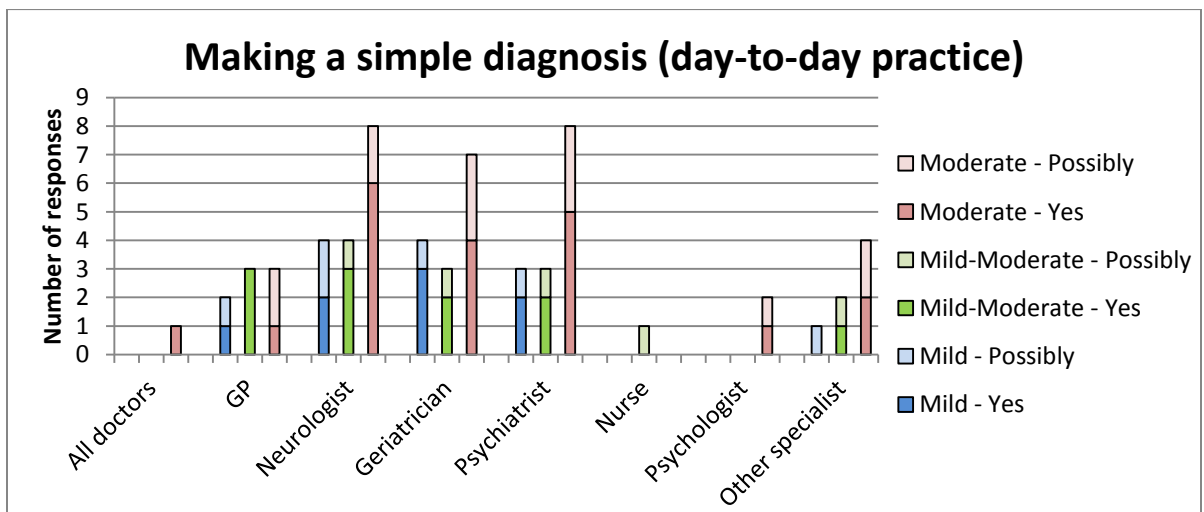
The main four professions are again GP, Neurologist, Geriatrician and Psychiatrist, with GP the least common of them. Again, Latvia and Ireland said that they had no guidelines in place, while Malta said that this role could be carried out by all doctors.

Figure 48: Making a diagnosis in simple cases



As for the previous question, the responses are separated based on average stage of diagnosis in Figure 49. Countries diagnosing at moderate stage are more likely to use Psychiatrists to make a simple diagnosis, and countries who diagnose at mild stage are slightly less likely to use GPs.

Figure 49: Making a diagnosis in simple cases in day-to-day practice based on average stage of diagnosis



**Who are officially designated to make a diagnosis in complex cases, and who actually does in day-to-day practice?**

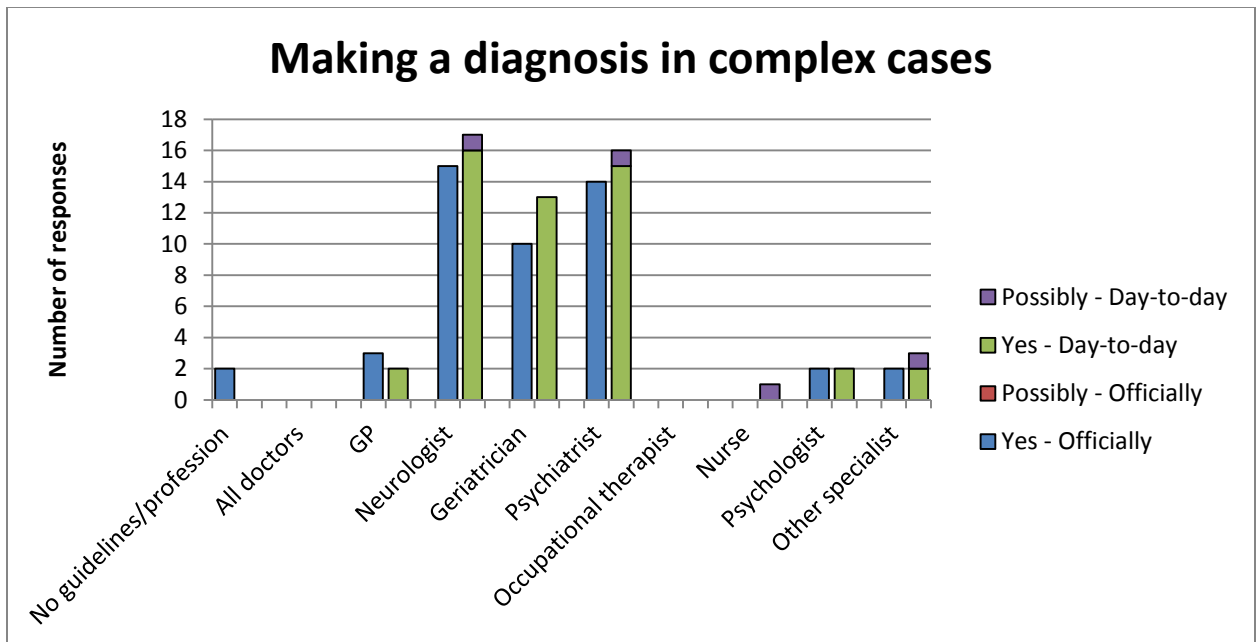
Number of responses: 17

Number of missing responses: 7

This question was added in to the new version of the questionnaire and so was not answered by any country filling in the original version. Overall, this question was not answered by: Bulgaria, Estonia, Lithuania, Greece, Malta, Belgium and Luxembourg.

This role is mainly carried out by Neurologists, Geriatricians and Psychiatrists, with GPs hardly mentioned. The official and actual responses are very similar. Latvia and Ireland said that they had no guidelines or no official designation for this role.

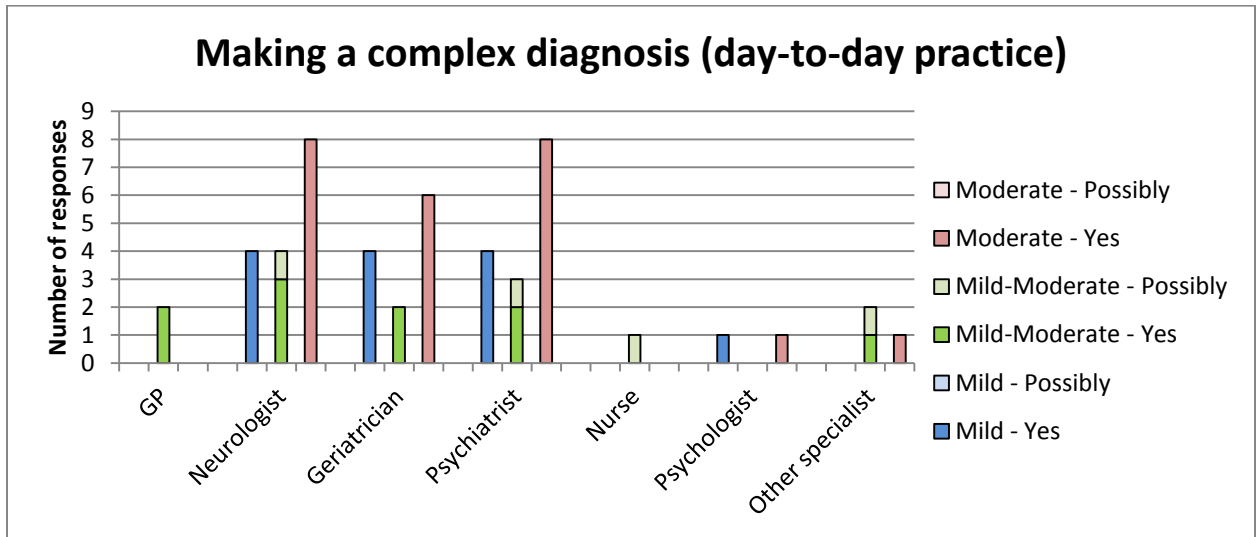
Figure 50: Making a diagnosis in complex cases



Again, the responses are considered separately depending on the stage at which diagnosis is made. As can be seen from Figure 51, Geriatricians are used for making a complex diagnosis slightly less often by countries who diagnose at mild-moderate or moderate stage. Countries diagnosing at mild-moderate stage are more likely to involve GPs. Taken with the responses from the two previous questions, this indicates that there is a connection between the professionals involved in the diagnostic process and the stage at which the diagnosis is made.



Figure 51: Making a diagnosis in complex cases in day-to-day practice based on average stage of diagnosis



### Who are officially designated to disclose diagnosis to patients and care givers, and who actually does in day-to-day practice?

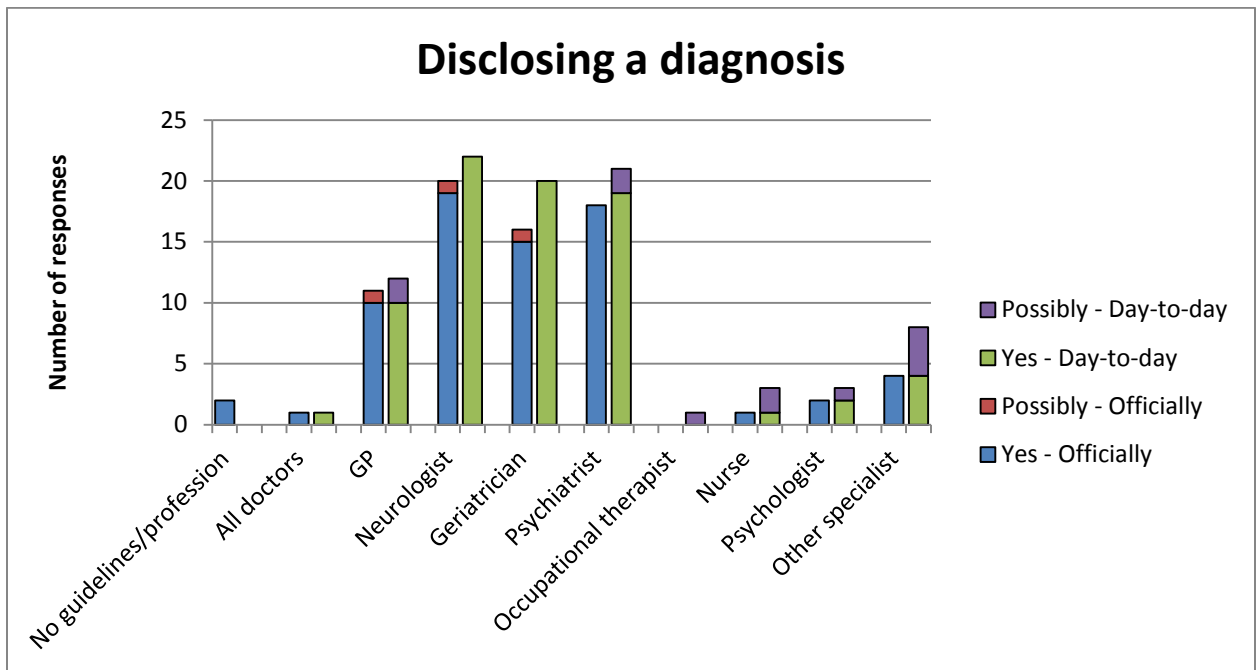
Number of responses: 23

Number of missing responses: 1

- This question was left blank by Bulgaria

Disclosing a diagnosis is mainly done by Neurologists, Geriatricians and Psychiatrists, with GPs also being fairly common. Again, Latvia and Ireland do not have guidelines or an official designation in place, and Malta said that the role can be carried out by any doctor.

Figure 52: Disclosing a diagnosis to patients and care givers



**Who are officially designated to determine an individual patient management strategy, and who actually does in day-to-day practice?**

Number of responses: 21/23

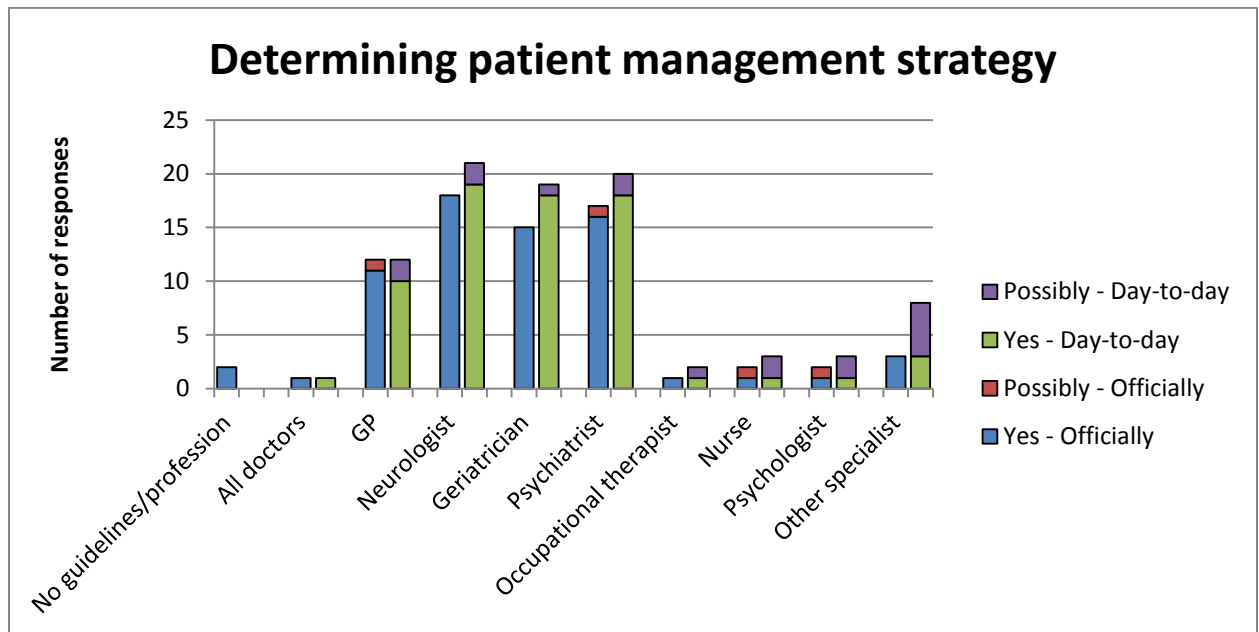
- The responses for Romania and Sweden were unclear

Number of missing responses: 1

- This question was left blank by Bulgaria

The responses are very similar to those for the previous question in terms of the main professions, but there is more involvement from other professions such as Occupational therapists, Nurses and Psychologists.

Figure 53: Determining an individual patient management strategy



### Who are officially designated to implement early psychosocial interventions, and who actually does in day-to-day practice?

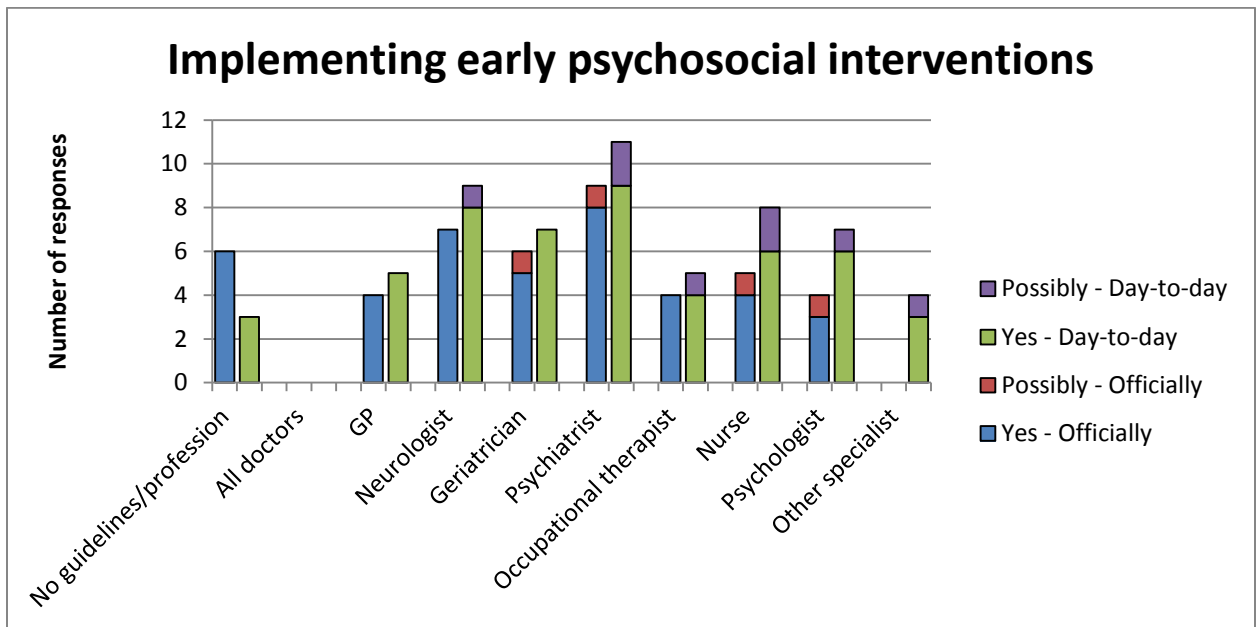
Number of responses: 17

Number of missing responses: 7

This question was added in to the new version of the questionnaire and so was not answered by any country filling in the original version. Overall, this question was not answered by: Bulgaria, Estonia, Lithuania, Greece, Malta, Belgium and Luxembourg.

The responses for this question are the most varied, with a whole range of professions involved, rather than three or four main ones. Six countries said that officially they had no guidelines in place, or there was no specific profession allocated to this role, with Hungary saying that in day-to-day practice no-one actually carried out this role.

Figure 54: Implementing early psychosocial interventions



### Who are officially designated to initiate anti-dementia drugs, and who actually does in day-to-day practice?

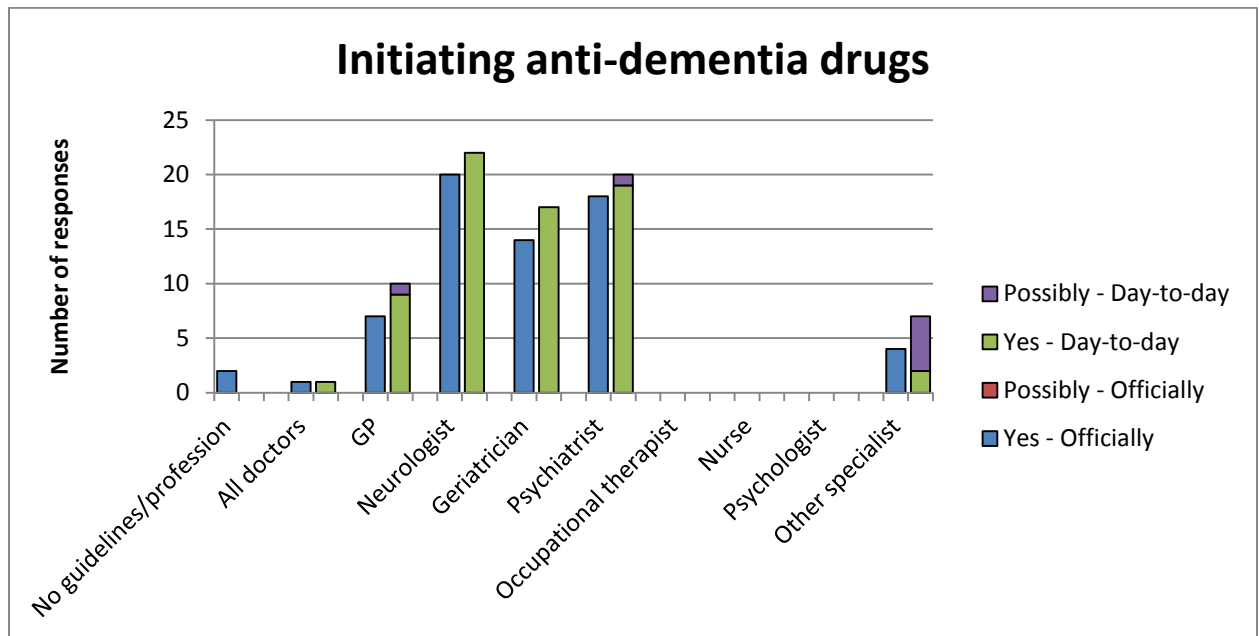
Number of responses: 23

Number of missing responses: 1

- This question was left blank by Bulgaria

The responses for this question return to the earlier pattern of the four main professions. Although a few countries said that 'other specialists' are involved, none said that Occupational Therapists, Nurses or Psychologists are able to initiate anti-dementia drugs.

Figure 5510: Initiating anti-dementia drugs



## Who are officially designated to ensure the follow-up of patients and carers, and who actually does in day-to-day practice?

### *Response information for official designation*

Number of responses: 20/23

- The responses for Romania, Sweden and Denmark were unclear

Number of missing responses: 1

- This question was left blank by Bulgaria

### *Response information for day-to-day practice*

Number of responses: 22/23

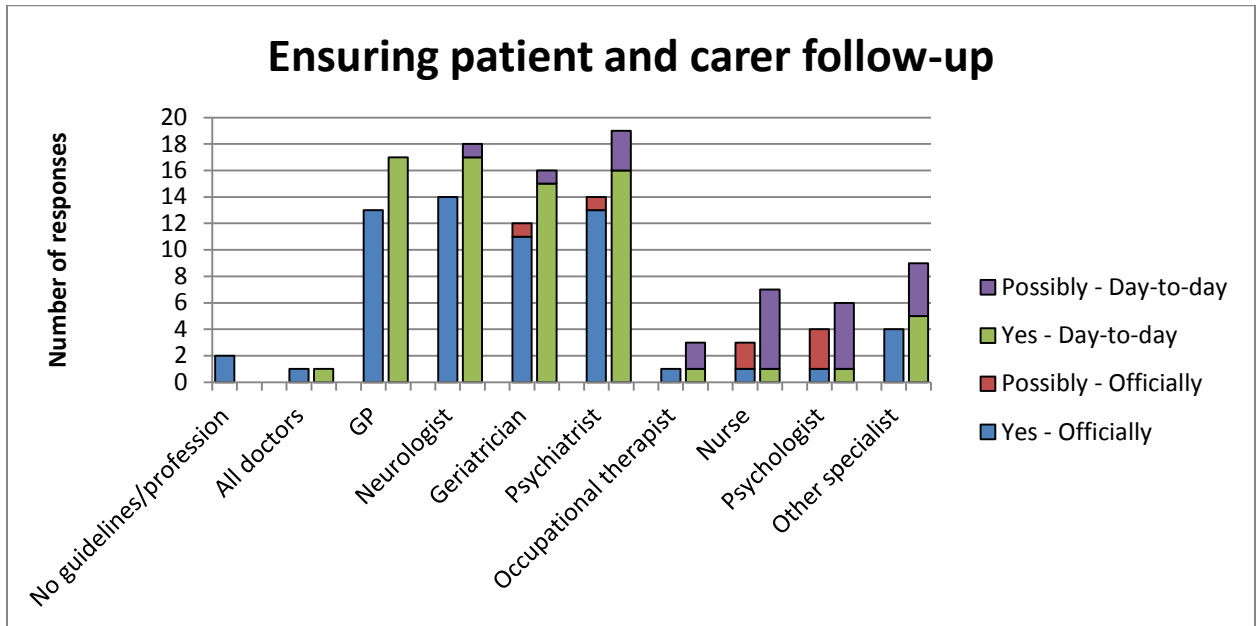
- The response for Romania was unclear

Number of missing responses: 1

- This question was left blank by Bulgaria

The four main professions are again key for ensuring patient and carer follow-up, but the responses indicate that a range of professions are actually involved. The other specialists included social workers and mental health nurses. It can be seen across all professions that actual day-to-day involvement is greater than officially recommended.

Figure 56: Ensuring the follow-up of patients and carers



**Who are officially designated to monitor anti-dementia drugs, and who actually does in day-to-day practice?**

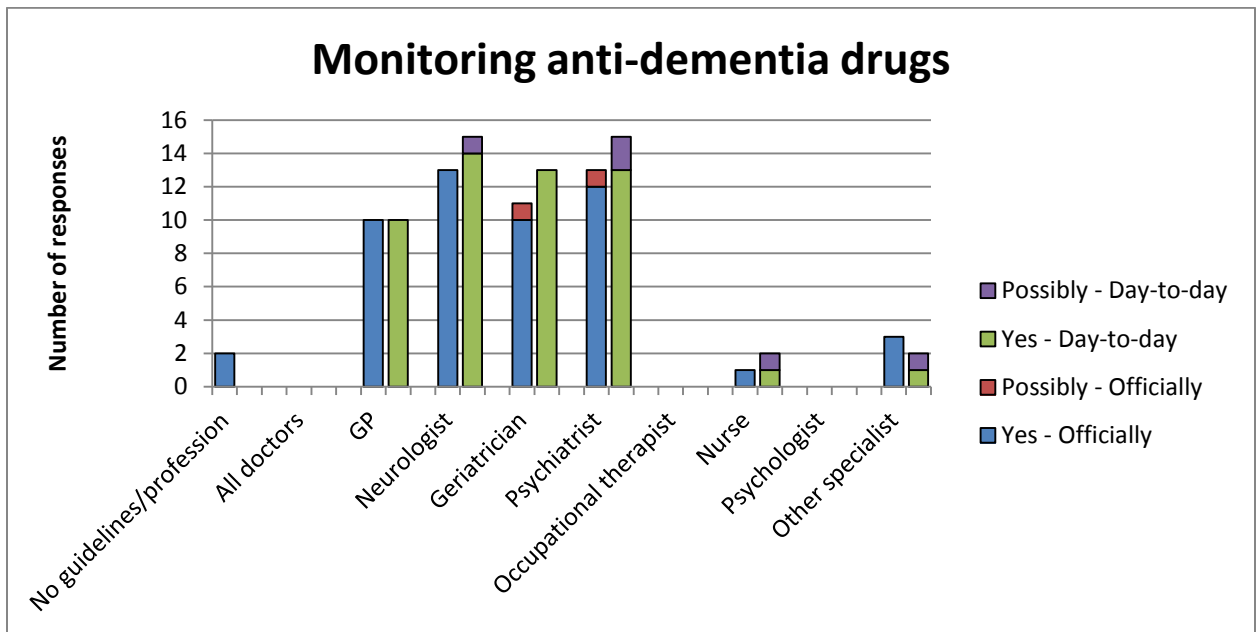
Number of responses: 17

Number of missing responses: 7

This question was added in to the new version of the questionnaire and so was not answered by any country filling in the original version. Overall, this question was not answered by: Bulgaria, Estonia, Lithuania, Greece, Malta, Belgium and Luxembourg.

For this role, the four main professions involved are GP, Neurologist, Geriatrician and Psychiatrist.

Figure 57: Monitoring anti-dementia drugs



**Who are officially designated to monitor adverse drug reactions, and who actually does in day-to-day practice?**

Number of responses: 22/23

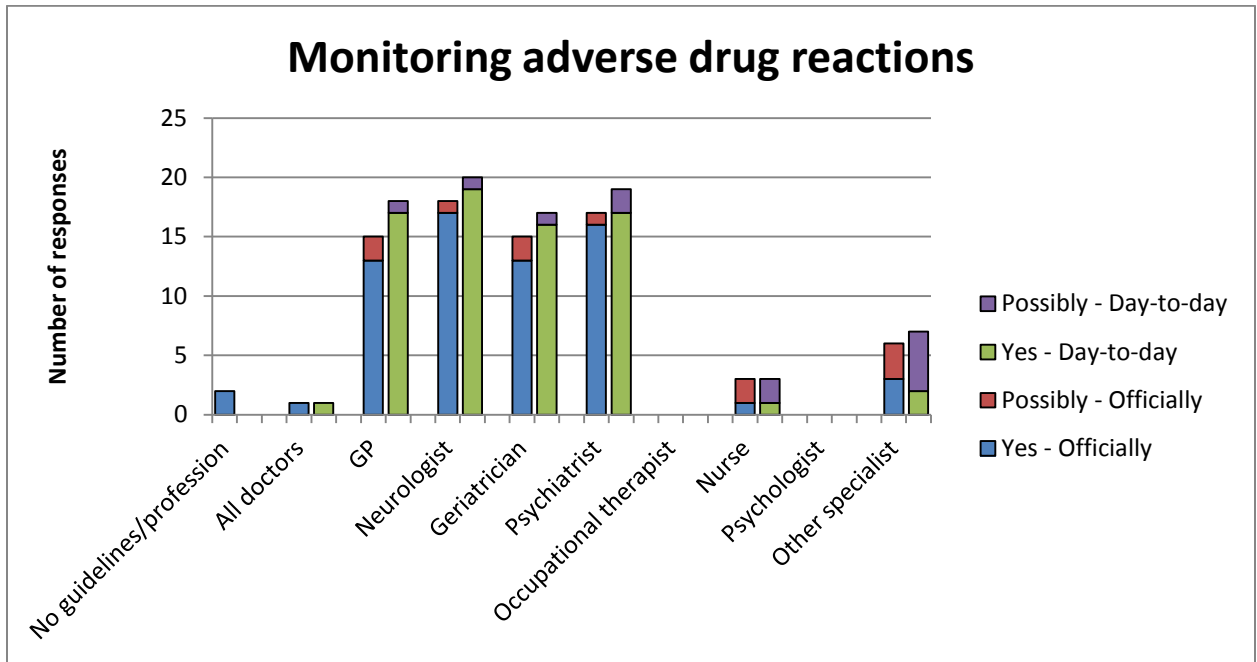
- The response for Denmark was unclear

Number of missing responses: 1

- This question was left blank by Bulgaria

The responses for this question are very similar to those given for the previous question.

Figure 58: Monitoring adverse drug reactions



**Who are officially designated to discontinue treatment, and who actually does in day-to-day practice?**

Number of responses: 23

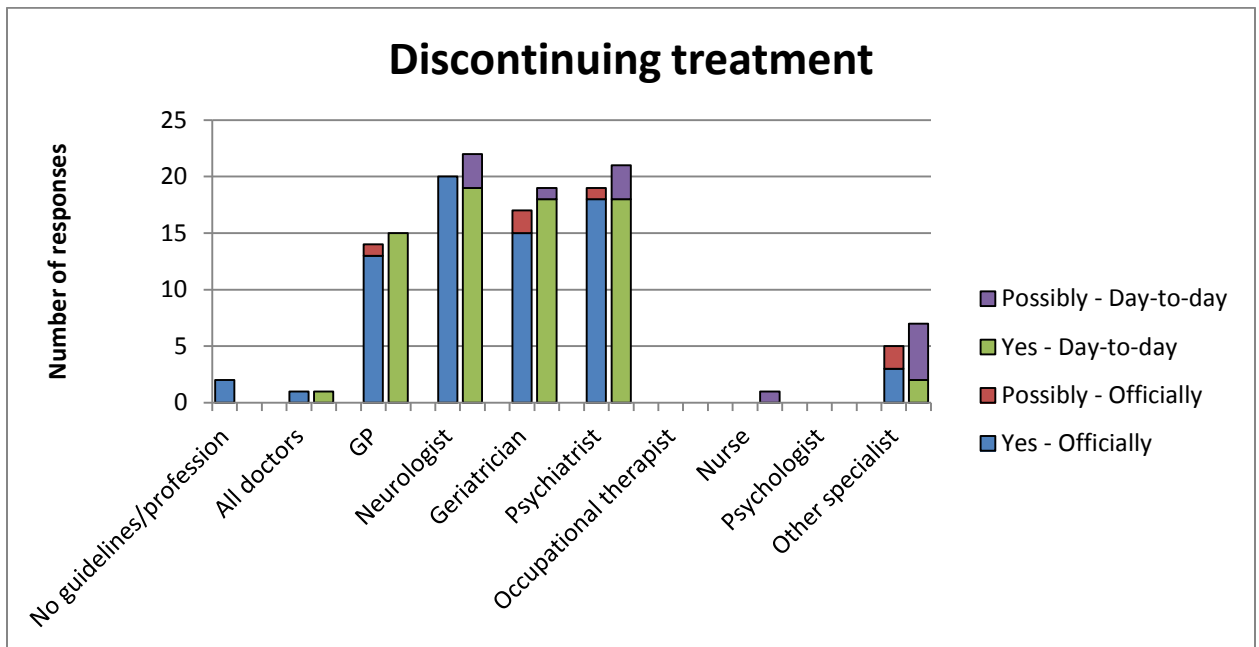
Number of missing responses: 1

- This question was left blank by Bulgaria

The responses for this question are again very similar to those for the previous couple of questions, with the four main professions being involved.



Figure 59: Discontinuing treatment



**Who are officially designated to monitor deterioration in cognitive function, and who actually does in day-to-day practice?**

Number of responses: 22/23

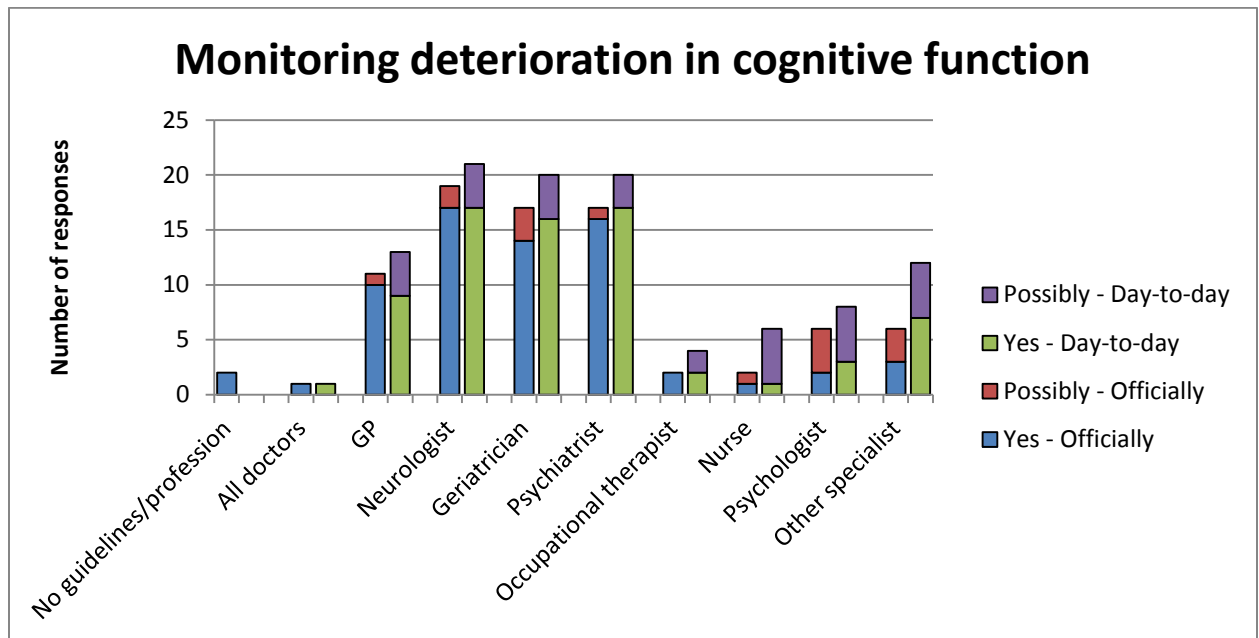
- The response for Sweden was unclear

Number of missing responses: 1

- This question was left blank by Bulgaria

Although the four main professions are again prominent, the whole range of professions is involved in monitoring deterioration in cognitive function. The other specialists include Neuropsychologists.

Figure 60: Monitoring deterioration in cognitive function



**Which psycho-social interventions does your country offer directly following diagnosis for people with dementia and their families, and how often?**

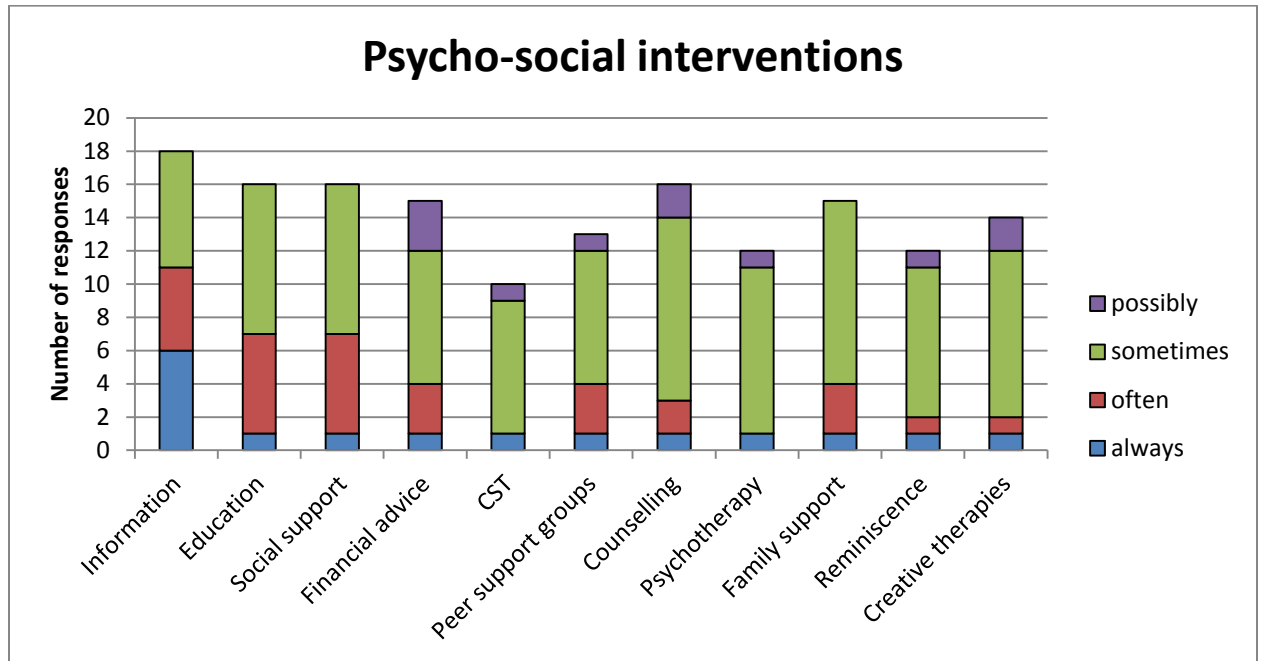
Number of responses: 18

Number of missing responses: 6

This question was added in to the new version of the questionnaire and so was not answered by any country filling in the original version, although attempts were made to get these countries to complete the new question. Overall, this question was not answered by: Bulgaria, Estonia, Germany, Greece, Malta and Belgium.

It can be seen from Figure 61 that the whole range of psycho-social interventions are quite popular, with Cognitive Stimulation Therapy (CST) being offered least often. It should be noted that Luxembourg responded that it always offers all of the interventions listed, and was the only country to do so.

Figure 61: Psycho-social interventions offered following diagnosis



## Legal framework

### Do you have legislation to protect vulnerable adults that includes people with dementia?

Number of responses: 22/23

- The response for Latvia was unclear

Number of missing responses: 1

- This question was left blank by Bulgaria

As can be seen from Figure 62, over half of the countries do have legislation in place to protect people with dementia, which is encouraging.

Figure 62: Whether countries have legislation to protect vulnerable adults, including people with dementia

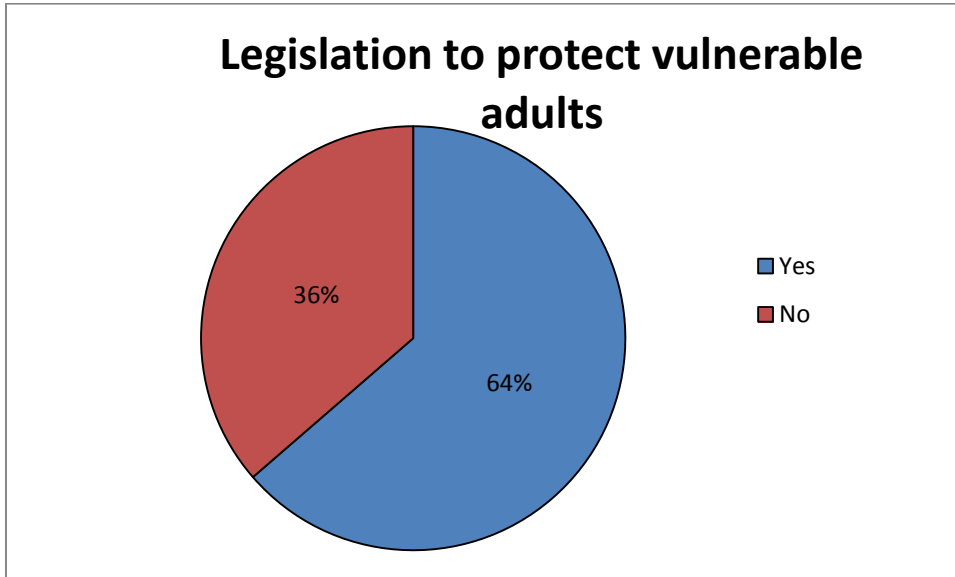
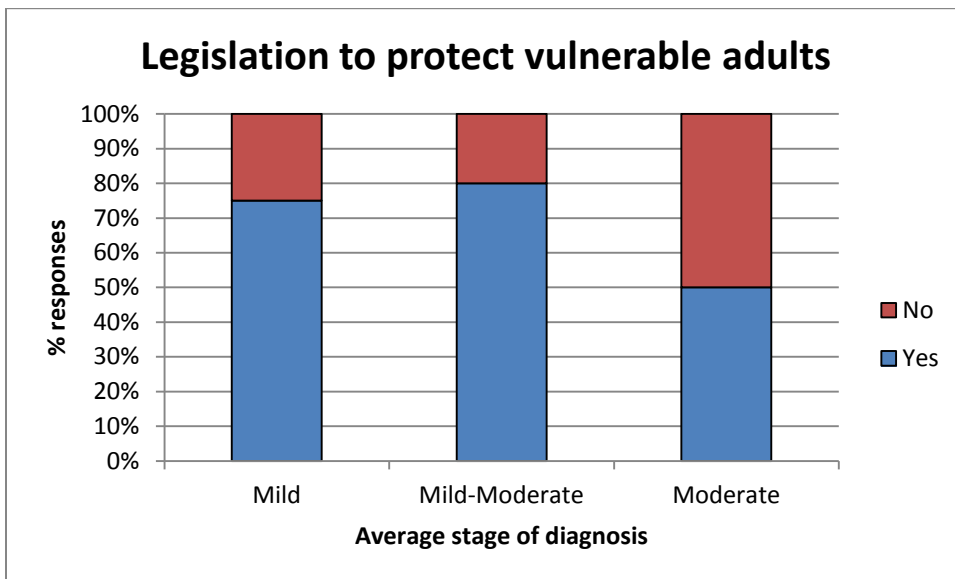


Figure 63 shows these responses separately based on the average stage at which diagnosis is made, and show that legislation to protect vulnerable adults is least likely to be in place in countries where diagnosis is made at moderate stage.

Figure 63: Whether countries have legislation to protect vulnerable adults, including people with dementia, based on average stage of diagnosis



**Do you have legislation for advance statements and advance directives?**

Number of responses: 20/22

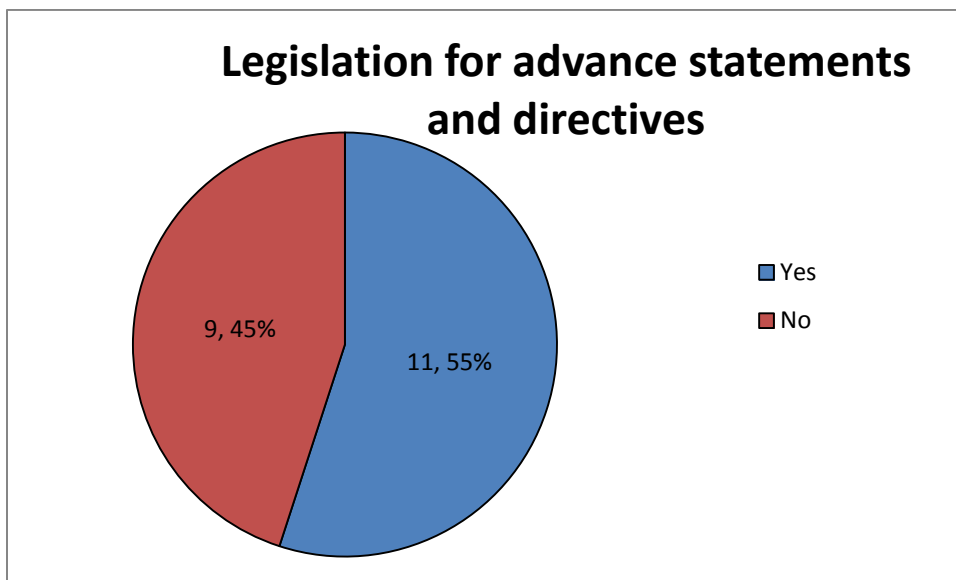
- The responses for Latvia and France were unclear

Number of missing responses: 2

- This question was left blank by Bulgaria and Estonia

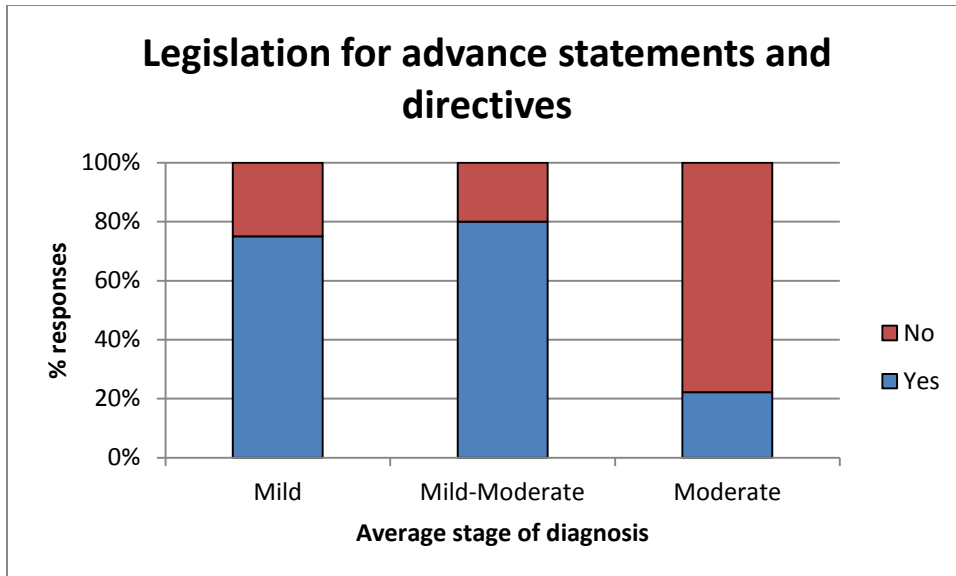
Legislation for advance statements and advance directives is less common than for the previous question, but over half of the countries do have such legislation in place. The 11 countries with the legislation were most likely to be from the Northern and Western regions of the EU. The full list of the 11 countries is: Belgium, Denmark, Finland, Germany, Italy, Luxembourg, Netherlands, Slovenia, Spain, Sweden and United Kingdom.

*Figure 64: Whether countries have legislation for advance statements and advance directives*



As with the previous question, legislation for advance statements and directives is least likely to be in place in countries where diagnosis is made at moderate stage.

*Figure 65: Whether countries have legislation for advance statements and advance directives, based on average stage of diagnosis*



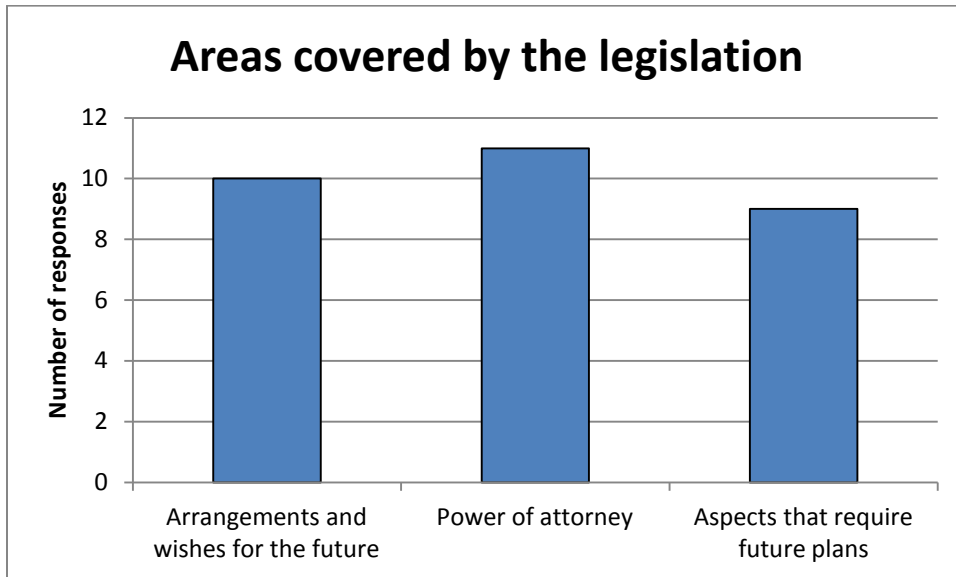
### What does this legislation include?

This question relates to the advance statements and advance directives, so only the responses from the 11 countries who replied 'yes' to having such legislation are considered.

Number of responses: 11

From Figure 66 it can be seen that of the 11 countries with legislation for advance statements and advance directives, almost all covered the same three key areas. The only differences were that in Denmark and Sweden the legislation does not cover aspects that require future plans, and in Italy it does not cover arrangements and wishes for the future. It should be noted that legislation in the United Kingdom also covers end of life care.

Figure 66: What areas are covered by the legislation for advance statements and advance directives



### Are GPs and specialists familiar with this legislation?

This question relates to the advance statements and advance directives, so only the responses from the 11 countries who replied 'yes' to having such legislation are considered.

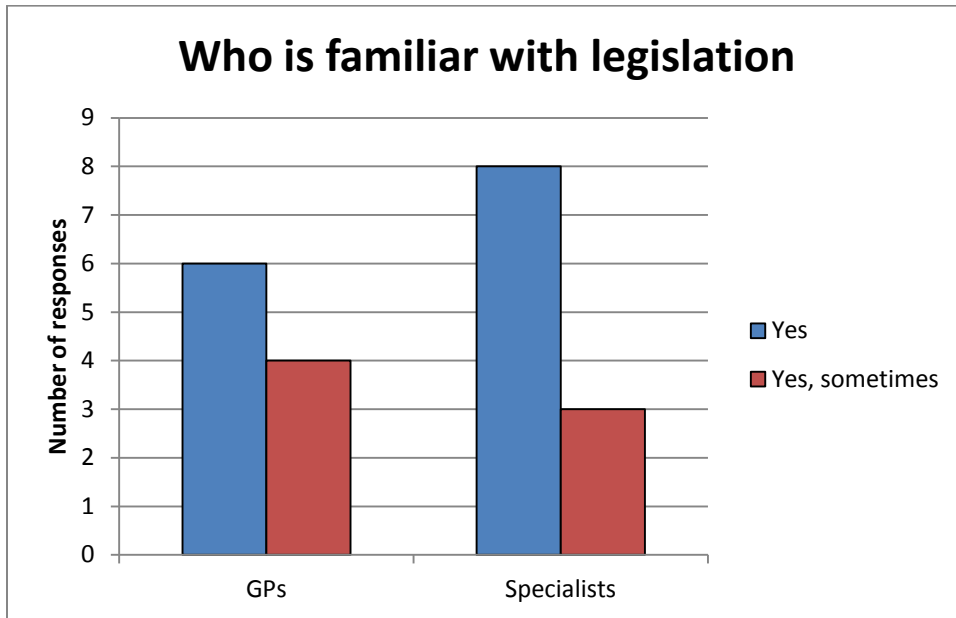
Number of responses for GPs: 10/11

- The response from Denmark was unclear

Number of responses for specialists: 11

It can be seen from Figure 67 that the responses are similar regarding whether GPs and specialists are familiar with the legislation for advance statements and advance directives. It is encouraging that although some countries responded that GPs and specialists are only 'sometimes' aware of the legislation, no country said that they are not aware of it at all.

Figure 67: Who is familiar with the legislation for advance statements and advance directives



### Who encourages patients to design an advance directive?

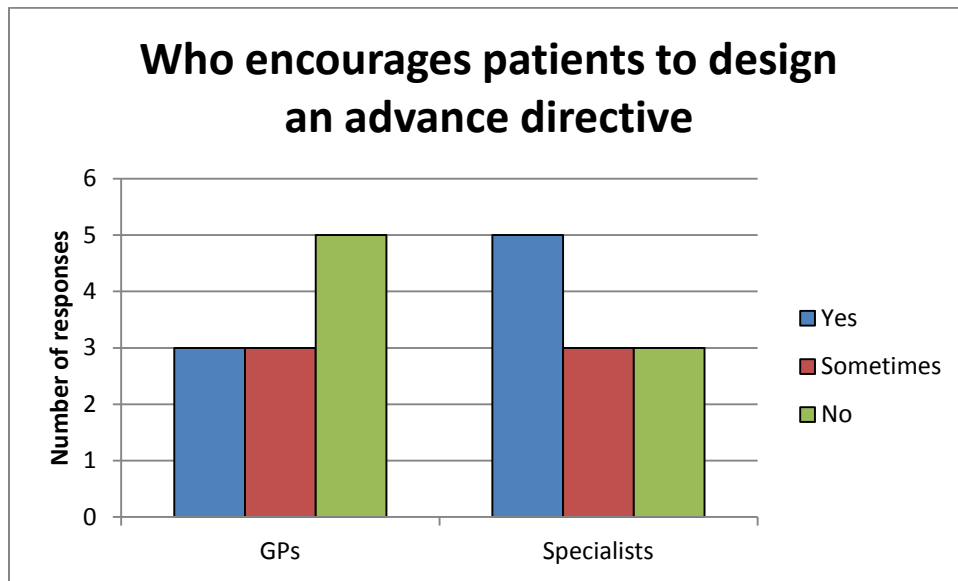
This question relates to the advance statements and advance directives, so only the responses from the 11 countries who replied 'yes' to having such legislation are considered.

Number of responses: 11

As can be seen from Figure 68, specialists are considered more likely to encourage patients to design an advance directive than GPs are. It should be noted that the United Kingdom response said that other health professionals are also sometimes involved in encouraging patients, including nurses, psychologists, occupational therapists and dementia advisers. Italy also said that others were involved in encouraging patients, giving their Alzheimer's Association as an example.



Figure 68: Who encourages patients to design an advance directive



### Who is responsible for the promotion of these legal provisions?

This question relates to the advance statements and advance directives, so only the responses from the 11 countries who replied 'yes' to having such legislation are considered.

Number of responses: 8/10

- The responses for Denmark and Spain were unclear

Number of missing responses: 1

- This question was left blank by Finland

The few responses that were received fell into a few broad categories:

- Medical professionals – GP, physician
- Government departments etc. – Ministry of Health, Ministry of Family and Integration, Ministry of Justice, Office of the Public Guardian
- Other – local courts
- No-one

Additional comments about the legislation were also made by a few countries, with the main points being:

- There are too many different legislations
- The legislation is “too weak to ensure patients the protection they need”

- Currently do not have legislation but it is being considered

## Health organisations

### Do you have specialist memory clinics?

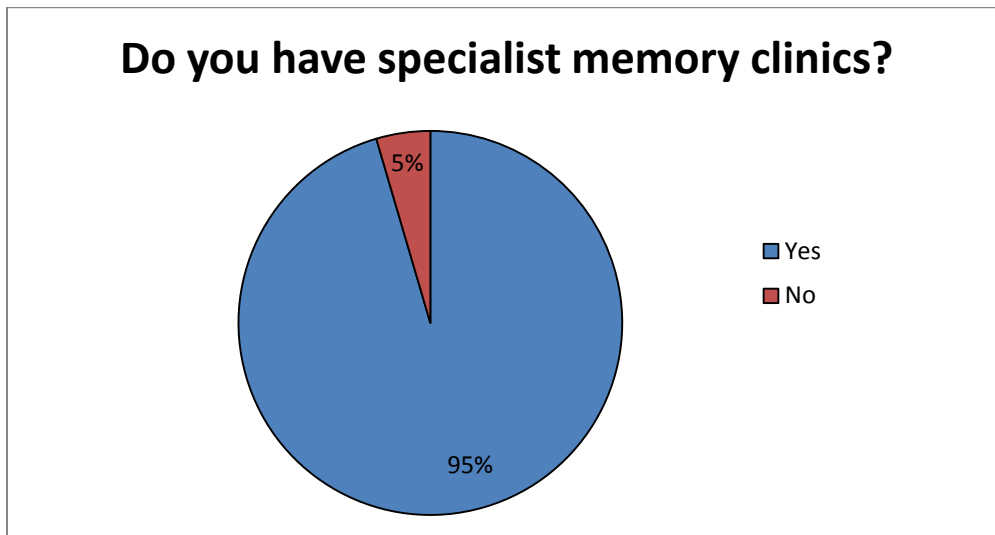
Number of responses: 22

Number of missing responses: 2

- This question was left blank by Bulgaria and Luxembourg

As can be seen from Figure 69 almost all countries said that they have specialist memory clinics. The only country that answered 'no' was Lithuania.

Figure 69: How many countries have specialist memory clinics



### How many memory clinics are there in your country?

This question was only relevant to the countries with memory clinics, so only the responses from the 21 countries who answered 'yes' to the previous question are considered.

Number of responses: 21

Variations in responses:

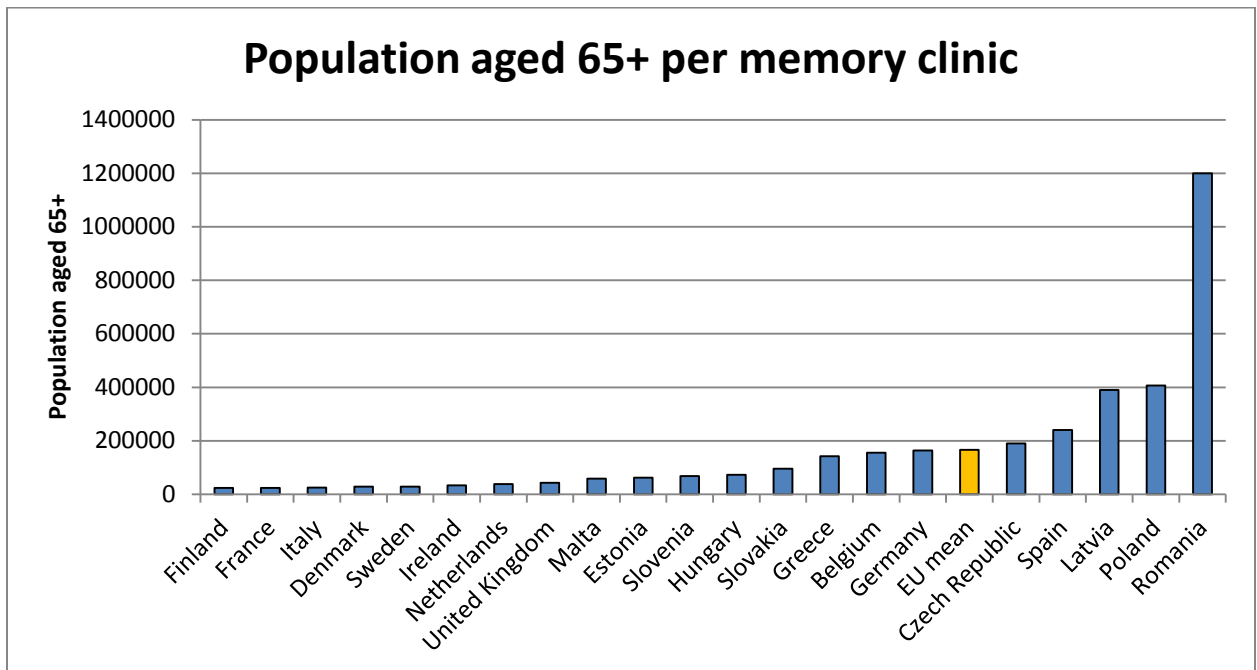
- Approximate values
- Specific values
- Ranges

- More than/less than

As with the number of different professionals in the Country Data section, the actual number of memory clinics is meaningless when comparing countries of different sizes and populations. The responses were therefore converted to the number of people aged 65+ per memory clinic, using the population information from the Country Data section. It can be seen from Figure 70 that there is a lot of variation between countries, ranging from one memory clinic per 23,526 people aged 65+ in Finland to one per 1.2 million people aged 65+ in Romania.

- Response verification for Romania – no information was found on the Internet, so the response given for Romania was taken at face value.

Figure 70: The number of people aged 65+ per memory clinic in each country

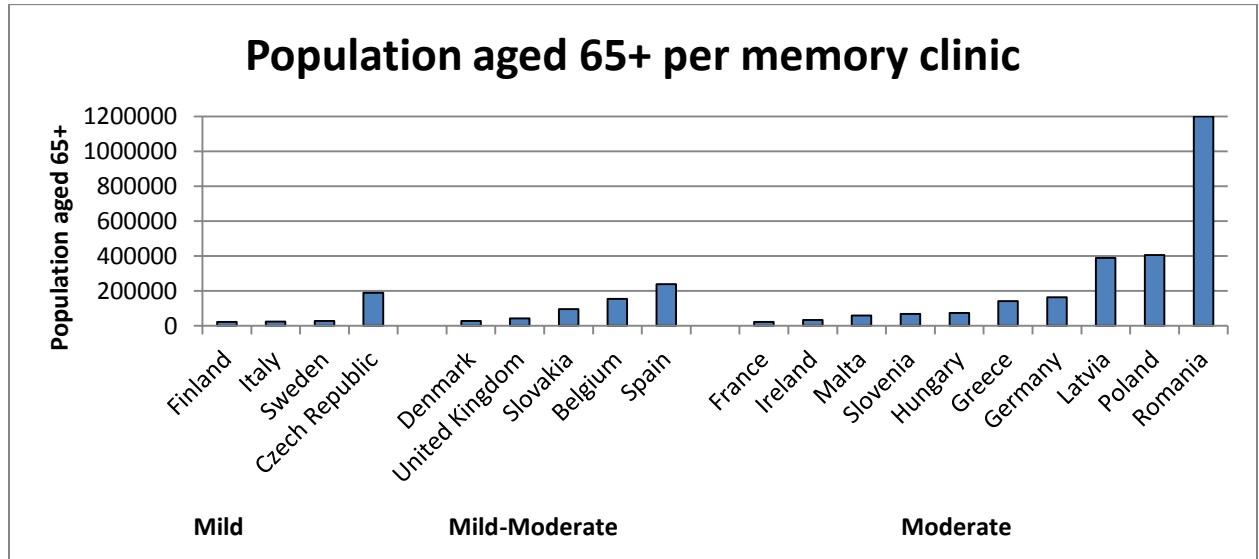


These responses were separated based on the average stage at which diagnosis is made in the different countries, as shown in Figure 71. Although the response from Romania skews the results slightly, it appears that as the stage of diagnosis gets later, the population aged 65+ per memory clinic increases. For the countries shown in Figure 71 the mean populations were:

- Mild stage diagnosis – 66,777 people aged 65+ per memory clinic
- Mild-moderate stage diagnosis – 112,472 people aged 65+ per memory clinic
- Moderate stage diagnosis – 256,125 people aged 65+ per memory clinic

This could indicate that diagnosis is easier to make at an earlier stage when a memory clinic has fewer potential users.

Figure 71: The number of people aged 65+ per memory clinic in each country, based on average stage of diagnosis



### How widespread are the memory clinics in your country?

This question was only relevant to the countries with memory clinics, so only the responses from the 21 countries who previously answered 'yes' are considered.

Number of responses: 10/11

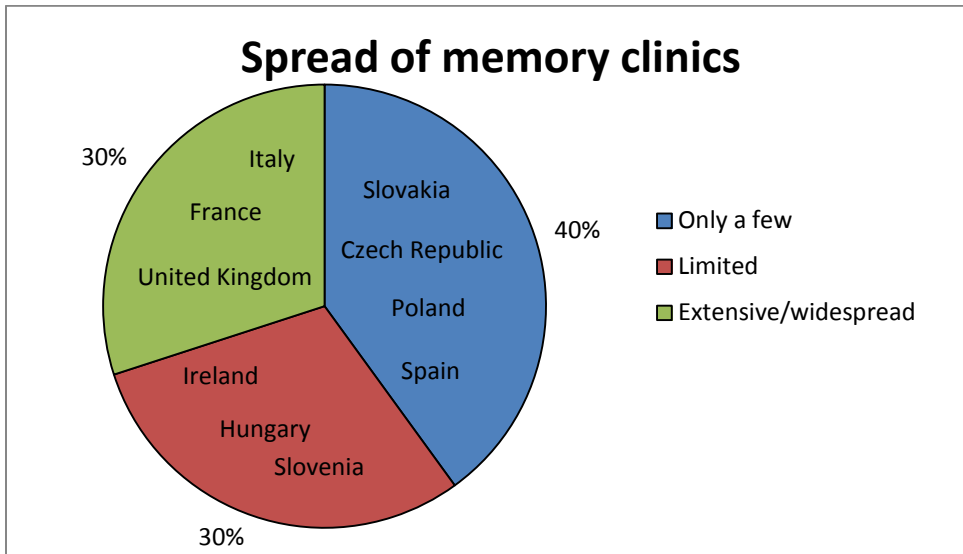
- The response for Latvia was unclear

Number of missing responses: 10

- This question was added in to the new version of the questionnaire and so was not answered by any country filling in the original version. Overall, this question was not answered by: Estonia, Romania, Finland, Netherlands, Germany, Sweden, Denmark, Greece, Malta and Belgium

Although only ten countries responded to this question, it can be seen from Figure 72 that almost all of them felt that the memory clinics in their country were far from widespread.

Figure 72: The spread of memory clinics in each country



**Do you have other types of expert memory services?**

Number of responses: 22/23

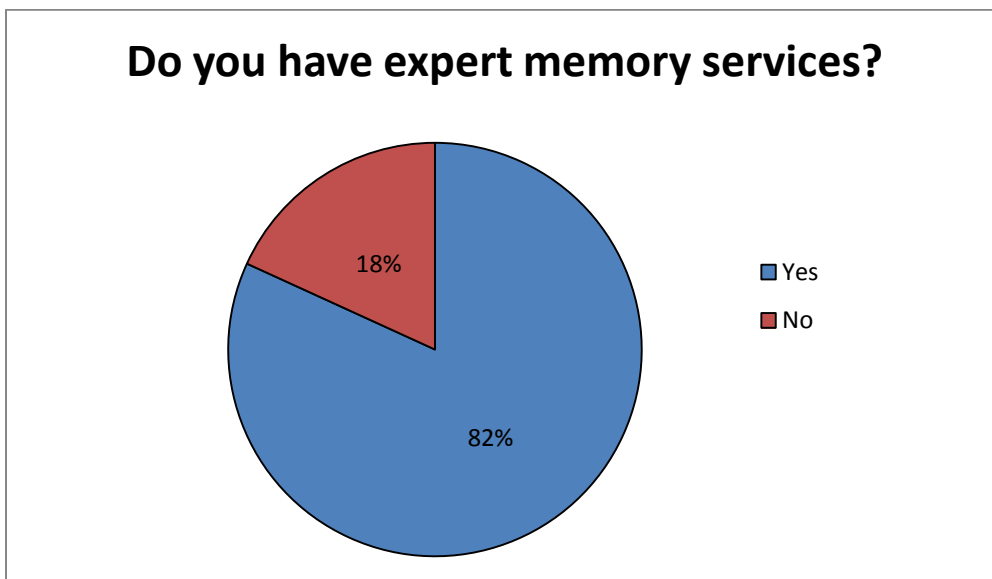
- The response for Ireland was unclear

Number of missing responses: 1

- This question was left blank by Bulgaria

Only four countries (Hungary, Finland, Italy, Luxembourg) said that they did not have any other expert memory services.

Figure 73: How many countries have expert memory services



## How many are there in your country?

This question was only relevant to the countries with other memory services, so only the responses from the 18 countries who answered 'yes' to the previous question are considered.

Number of responses: 15/18

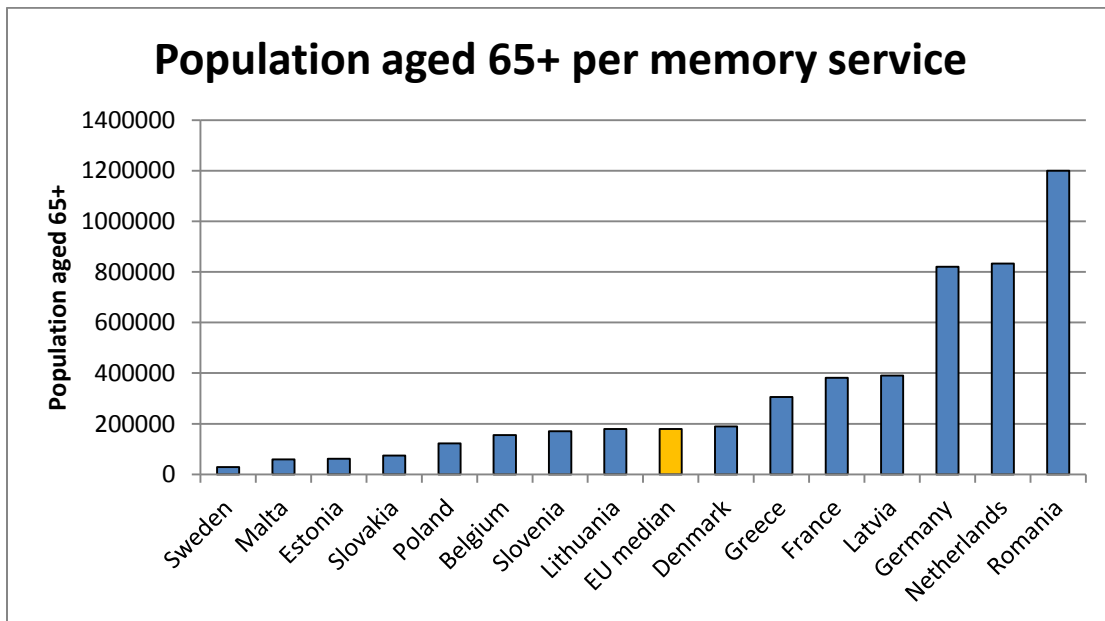
- The responses for Czech Republic, Spain and United Kingdom were unclear or did not include figures

Variations in responses:

- Approximate values
- Specific values
- Ranges
- More than/less than
- Descriptions of the services, but no actual numbers

As with the memory clinics, there is a lot of variation between countries, with Romania again having the highest number of people aged 65+ per memory service. The types of memory service mentioned in the responses included clinical research teams, Alzheimer's centres and multidisciplinary teams.

Figure 74: The number of people aged 65+ per memory service in each country



## How widespread are the memory services in your country?

This question was only relevant to the countries with memory services, so only the responses from the 18 countries who previously answered 'yes' are considered.

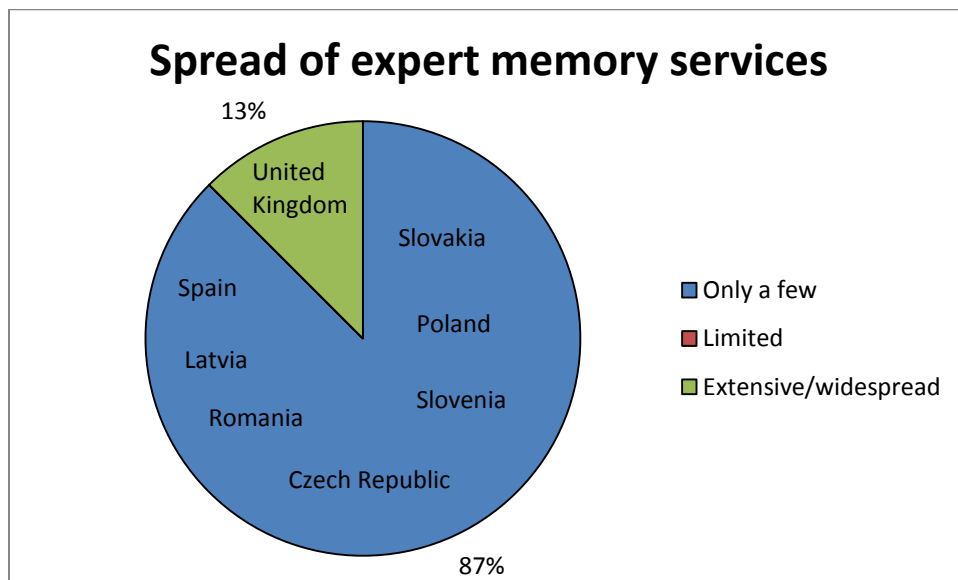
Number of responses: 8

Number of missing responses: 10

- This question was added in to the new version of the questionnaire and so was not answered by any country filling in the original version. Overall, this question was not answered by: Estonia, Lithuania, Netherlands, Germany, Sweden, Denmark, Greece, Malta, Belgium and France

The situation for expert memory services is worse than for memory clinics, as countries say that there are only a few of them rather than being limited. Again, the United Kingdom is the only country to consider the services to be widespread.

Figure 75: The spread of expert memory services in each country



## What is the average waiting time from referral to see a specialist for a memory assessment?

Number of responses: 16/21

- Belgium and Luxembourg said that data was unknown or not available
- The responses for Latvia, Romania and Denmark were unclear as there was too much variation between different responses

Number of missing responses: 3

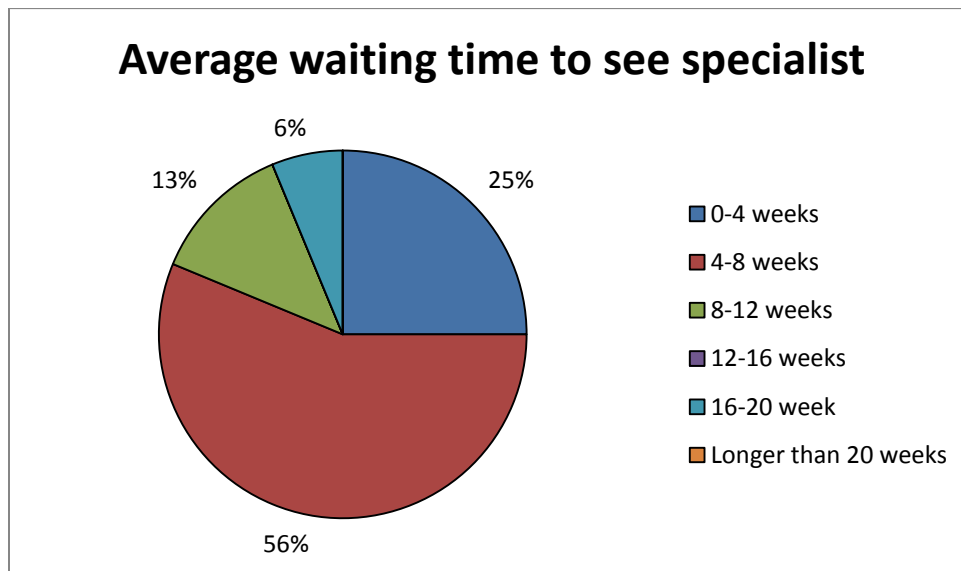
- This question was left blank by Bulgaria, Slovenia and Czech Republic

Variations in responses:

- Ranges
- Approximate times
- Times in days, weeks and months

The majority of countries (81%) responded that the average waiting time was eight weeks or less, with nearly a third of those actually being four weeks or less. The country that stood out as being different was Ireland, where the waiting time is said to be in the range of 16-20 weeks. No country had a waiting time longer than 20 weeks.

*Figure 76: The average waiting time from referral to see a specialist for a memory assessment*

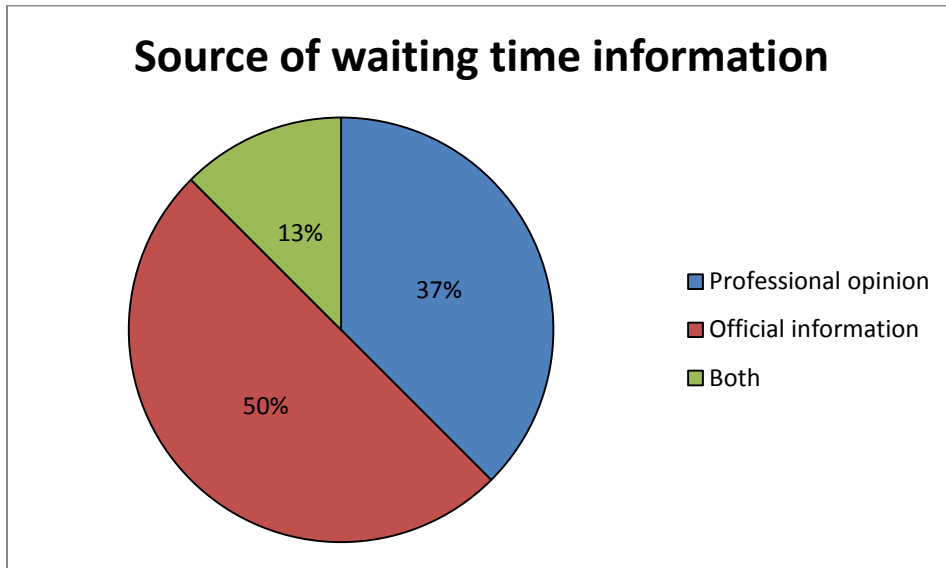


In terms of the source of this information, Figure 77 indicates that there was a fairly even split between official information and professional opinion. Examples of the official information used include:

- Health insurance
- Surveys
- Memory clinics
- Health organisations and registers



Figure 77: Source of information regarding the average waiting time from referral to see a specialist for a memory assessment



**In your perception, is the memory assessment service accessible to all patients?**

Number of responses: 22/23

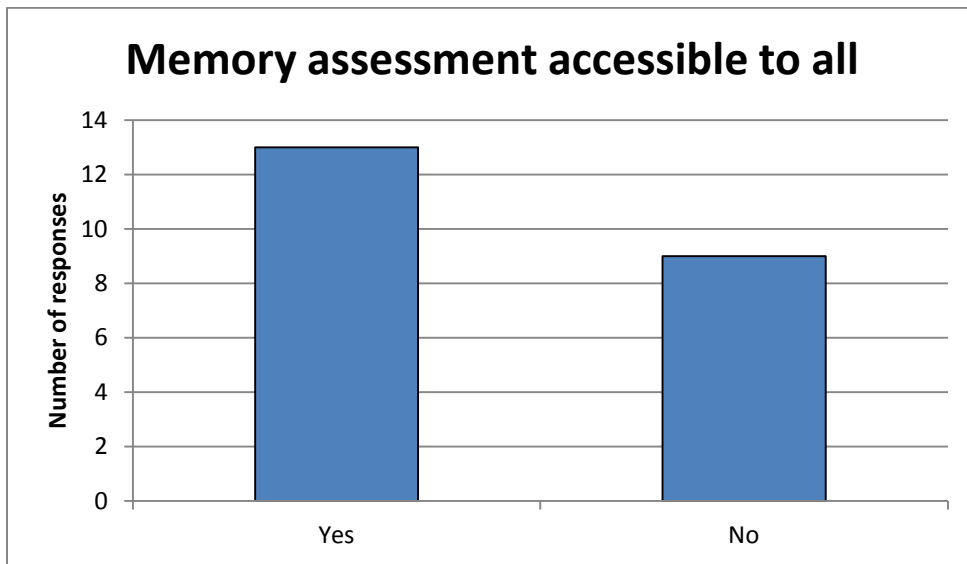
- The response for Slovakia was unclear

Number of missing responses: 1

- This question was left blank by Bulgaria

Although Figure 78 shows that most countries think that the memory assessment service is accessible to all, a large proportion (41%) do not agree.

Figure 78: Whether the memory assessment service is accessible to all patients



### What percentage of your country is covered by memory centres?

Number of responses: 21

Number of missing responses: 3

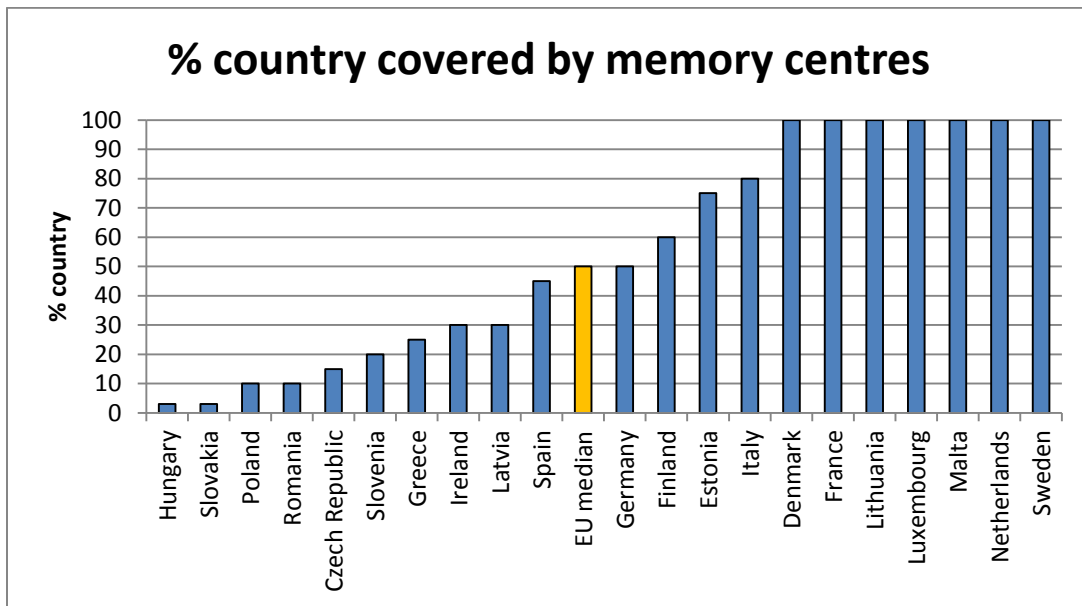
- This question was left blank by Bulgaria, Belgium and United Kingdom

Variations in responses:

- More than/less than
- Ranges
- Approximate values
- Specific values
- Number of residents and population sizes

As can be seen from Figure 79, there is a lot of variation between countries, but a number of countries did respond that 100% of their country was covered by memory centres, which is encouraging.

Figure 79: The percentage of each country covered by memory centres



### What percentage of your country is covered by dementia specialists?

Number of responses: 20/21

- The response for Latvia was unclear

Number of missing responses: 3

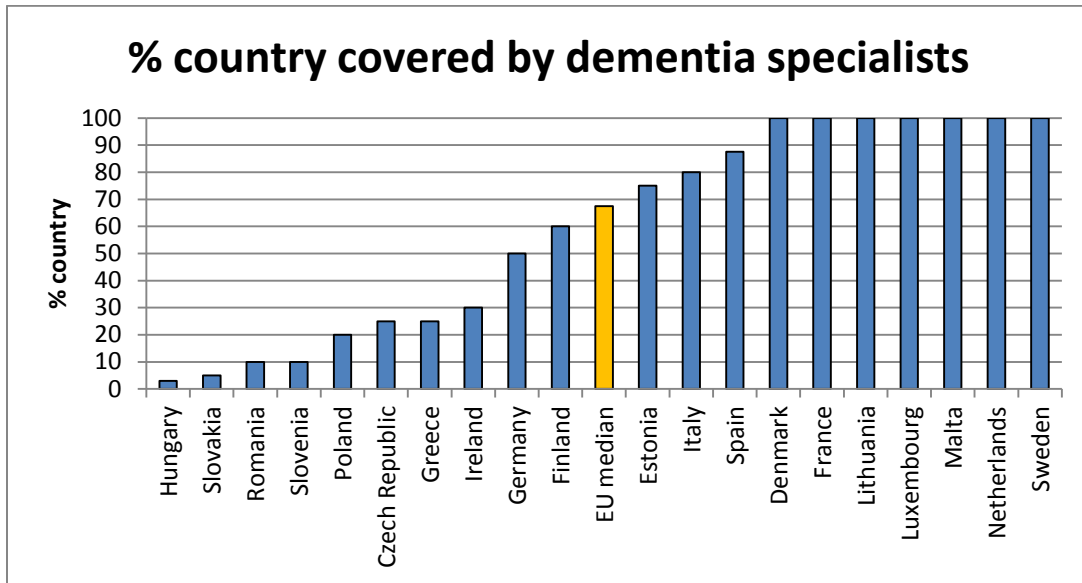
- This question was left blank by Bulgaria, Belgium and United Kingdom

Variations in responses:

- Less than
- Ranges
- Approximate values
- Specific values

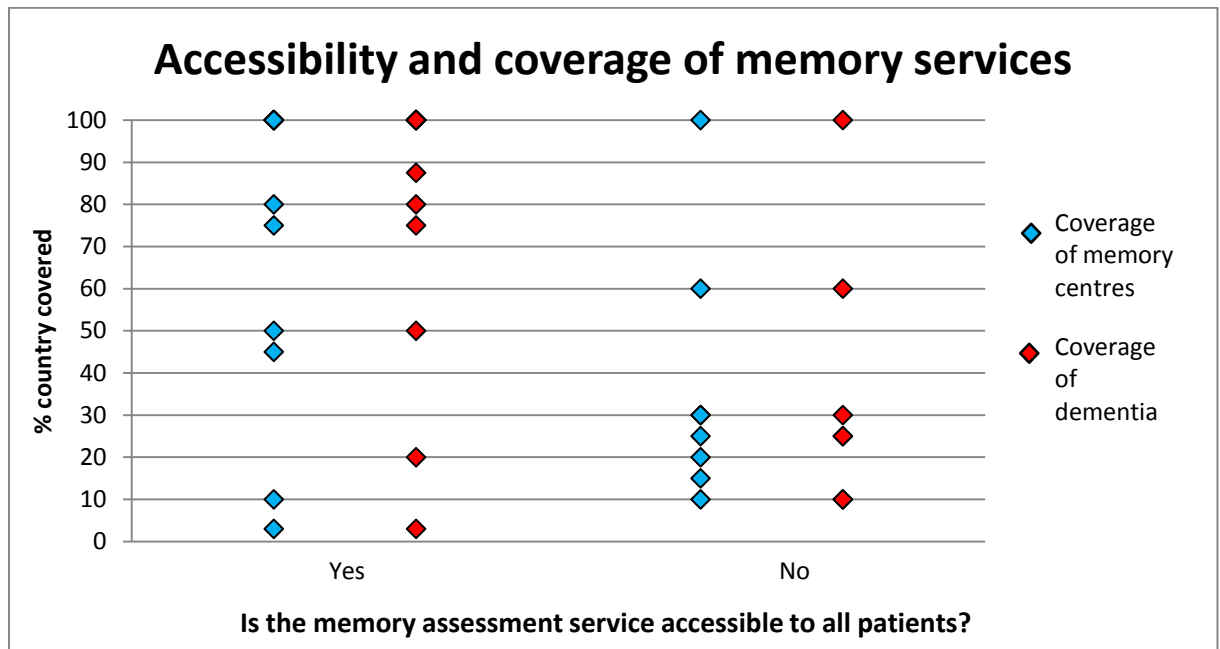
Coverage by dementia specialists appears to be slightly better than by memory centres, with a number of countries again responding with 100%.

Figure 80: The percentage of each country covered by dementia specialists



By looking at the coverage responses in terms of whether a country considered their memory services to be accessible to all patients (Figure 81) it can be seen that different countries responded in different ways. For example, Hungary considers their services to be accessible to all, but says that only 3% of the country is covered by memory centres and dementia specialists. Conversely, Sweden says that 100% of the country is covered by memory centres and dementia specialists, but does not consider its memory services to be accessible to all patients. These examples illustrate that opinions in different countries are very varied, and may indicate that questions are interpreted or understood differently by different countries.

Figure 81: Accessibility and coverage of memory services



**Are there specific centres for younger patients with suspected or established dementia?**

Number of responses: 22/23

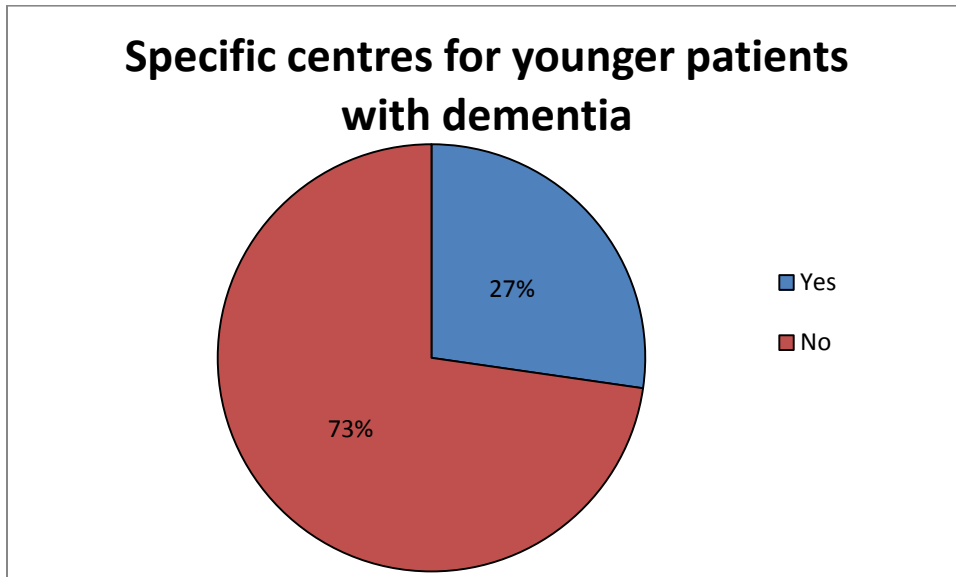
- The response for Slovakia was unclear

Number of missing responses: 1

- This question was left blank by Bulgaria

Although responses were more positive among the Northern and Western countries, the majority of countries (73%) say that they do not have specific centres for younger patients.

Figure 82: Whether there are specific centres for younger patients with suspected or established dementia



**Have there been communication campaigns organised to raise awareness about dementia?**

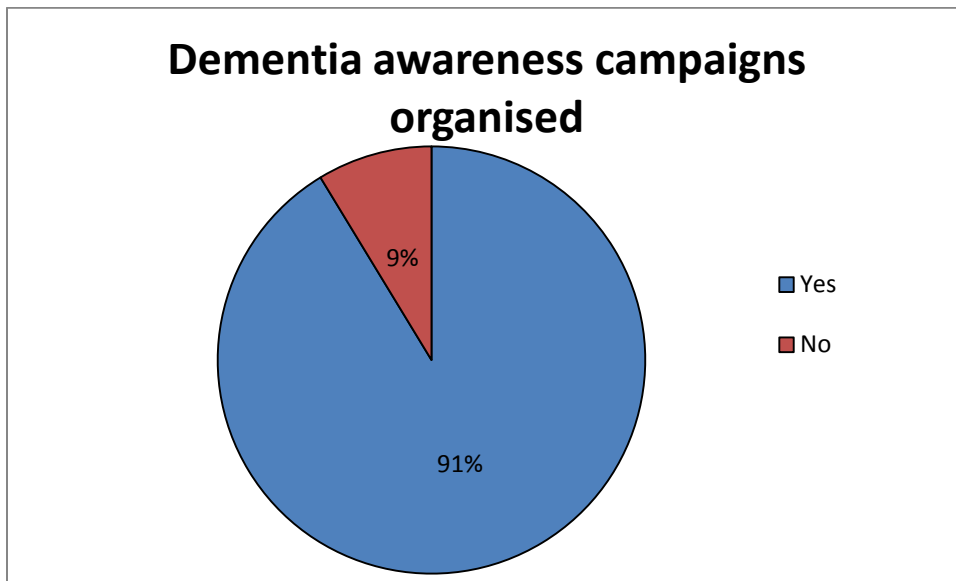
Number of responses: 23

Number of missing responses: 1

- This question was left blank by Bulgaria

The very positive picture from Figure 83 shows that almost all countries have communication campaigns to raise awareness about dementia. The only two countries to say no were Hungary and Finland.

Figure 83: Whether there are awareness campaigns for dementia



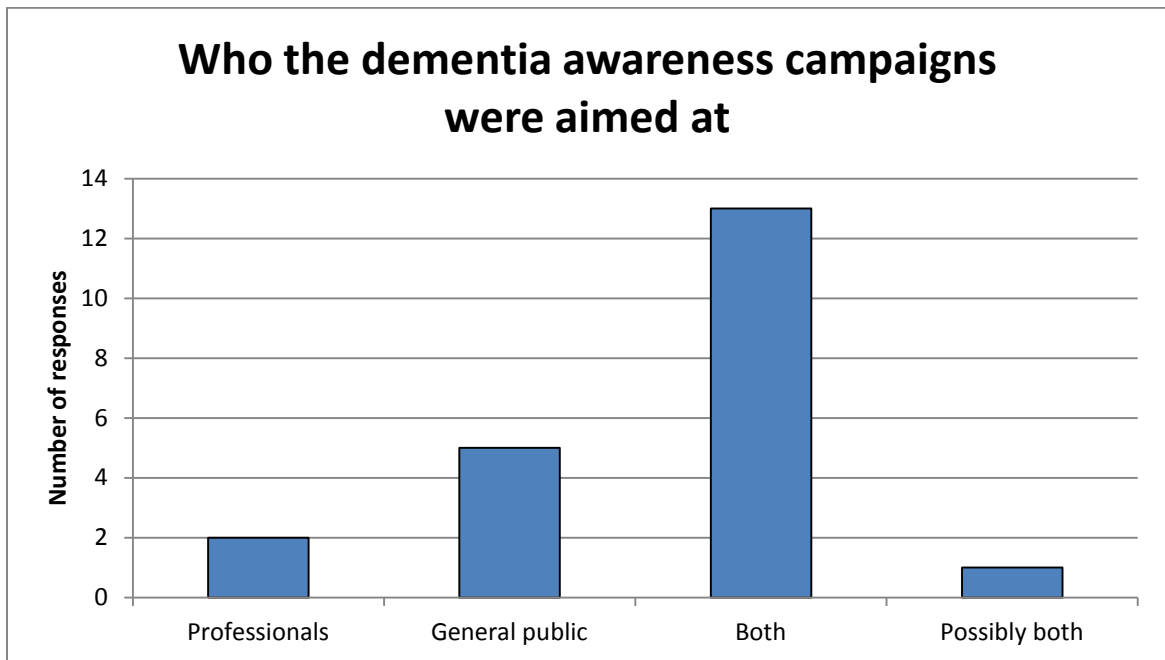
### Who were the campaigns aimed at?

This question was only relevant to the countries with communication campaigns, so only the responses from the 21 countries who previously answered 'yes' are considered.

Number of responses: 21

As can be seen from Figure 84, the dementia awareness campaigns were mainly aimed at both professionals and the general public, rather than one group or the other. In terms of the website links for the campaigns, 14 countries listed at least one site which appears to be a national Alzheimer's or dementia group. The other sites given were generally public health/department of health official sites.

Figure 84: Who the dementia campaigns were aimed at



### Does your country have specific policies to improve the quality of diagnosis?

Number of responses: 23

Number of missing responses: 1

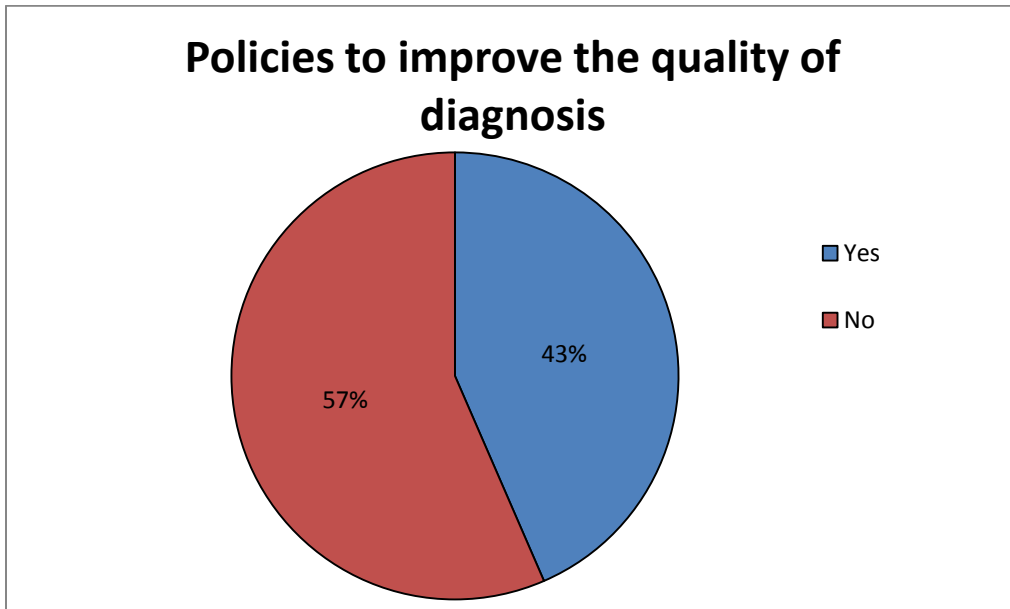
- This question was left blank by Bulgaria

Less than half of the countries (43%) said that they have policies in place to improve the quality of diagnosis. Examples given included:

- Alzheimer Society projects/action plans
- Government/parliament action plans/strategies
- National and/or local dementia guidelines/plans
- Department of Health guidance

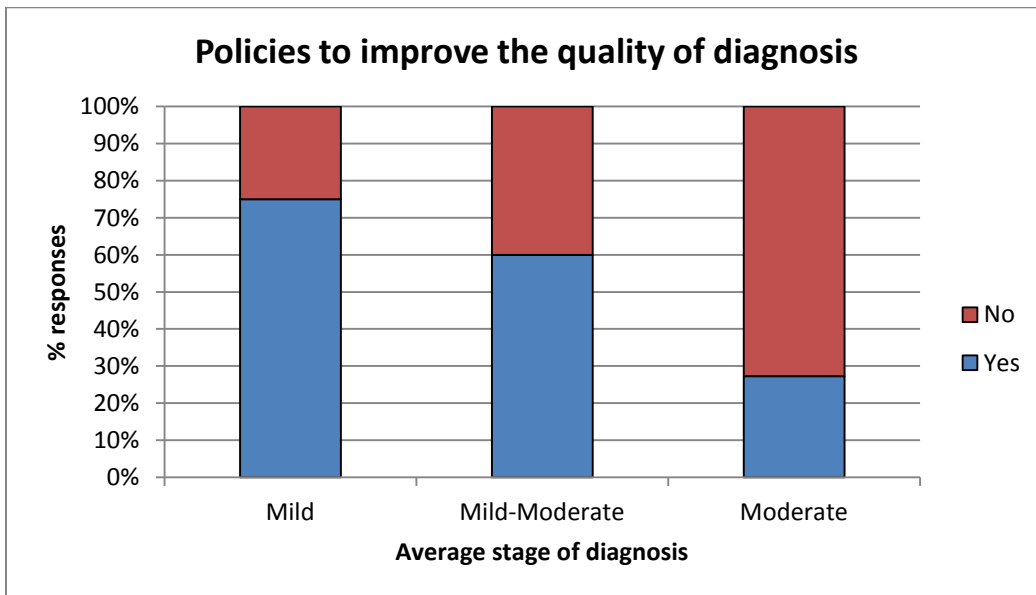


Figure 85: Whether there are policies to improve the quality of diagnosis



These responses are considered separately in Figure 86 based on the average stage at which a diagnosis is made. As might be expected, policies to improve the quality of diagnosis are more likely to be in place in countries where diagnosis is made earlier than in countries where the diagnosis is at a later stage.

Figure 86: Whether there are policies to improve the quality of diagnosis, based on average stage of diagnosis



## Are there examples of overarching/integrated dementia pathways from pre-diagnosis to end of life and beyond?

Number of responses: 19/22

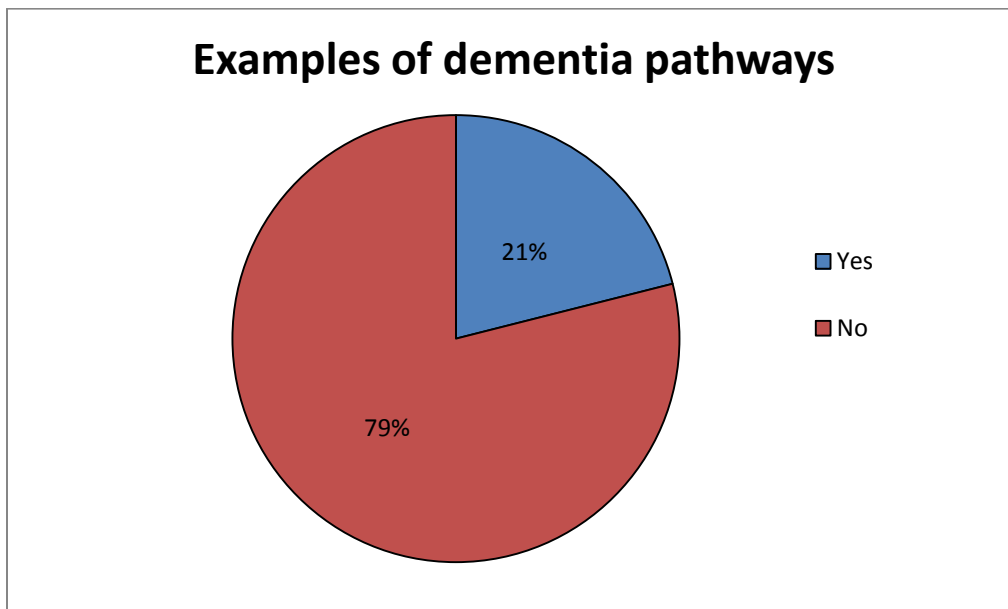
- Germany said that this was not known
- The responses for Denmark and France were unclear

Number of missing responses: 2

- This question was left blank by Bulgaria and Finland

Only four countries (Netherlands, Sweden, Italy and United Kingdom) responded 'yes' to this question, indicating that there is room for significant improvement.

Figure 87: Whether there are overarching/integrated dementia pathways



## Relationships between GPs and specialists

### What information is the GP supposed to give to the specialist when referring a patient?

Number of responses: 18/22

- The response for France was unclear
- The responses for Malta and Belgium were comments, rather than information
- The response for Greece said that there is "no liaising between GPs and specialists"

Number of missing responses: 2

- This question was left blank by Bulgaria and Hungary

Variations in responses:

- Descriptions
- Comments
- Standardised responses for the new version of the questionnaire

The information that should be provided by the GP to the specialist is shown in Figure 88, where it can be seen that clinical history is the most popular information required. A breakdown of the 'other' information is shown in Figure 89. The majority of this information relates to the results from different assessments already carried out by the GP.

*Figure 88: Information that should be provided by the GP to the specialist*

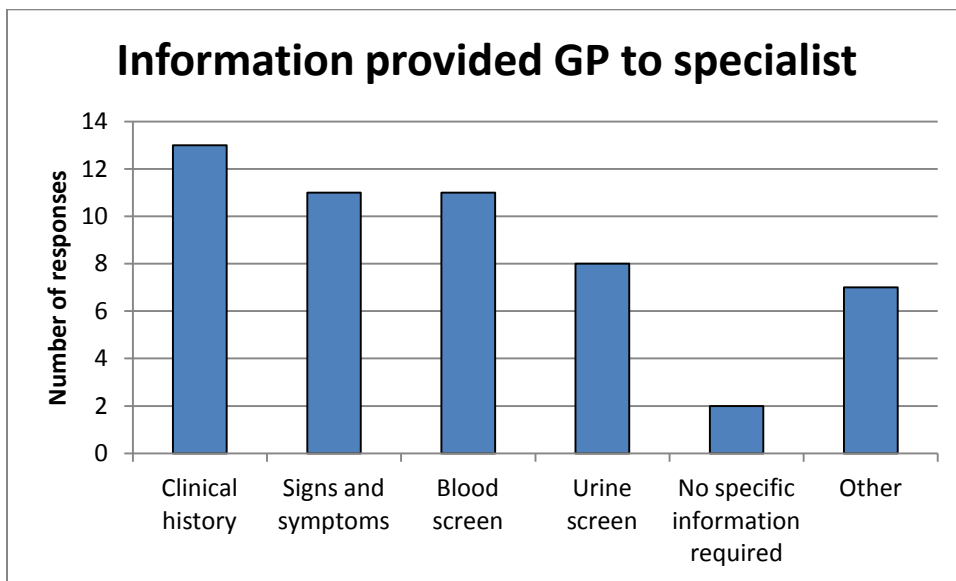
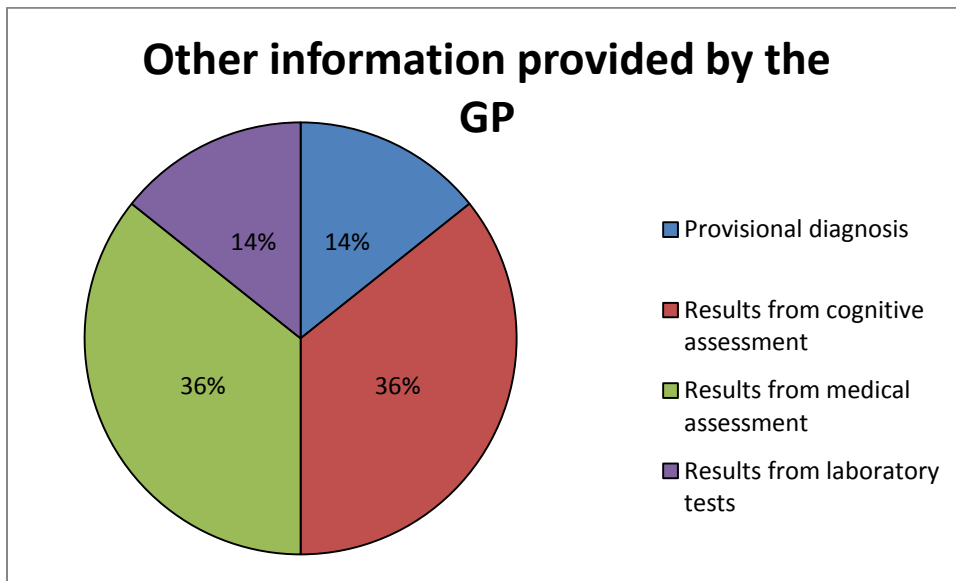


Figure 89: Other information provided by the GP to the specialist



### How often is this information actually shared GP to specialist?

Number of responses: 19/20

- The response for Malta was a comment rather than information, saying that most of the GPs do not refer patients to specialists

Number of missing responses: 4

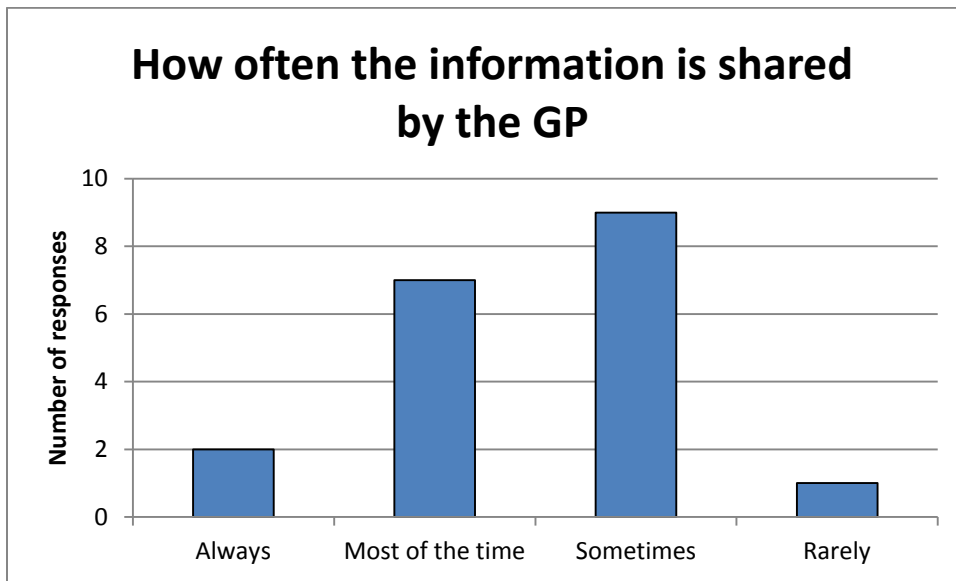
- This question was left blank by Bulgaria, Hungary, Greece and United Kingdom

Variations in responses:

- The information provided (the original question asked for this, rather than how often. In these cases, it was compared against the information required and given an appropriate answer from the new standardised responses of 'always', 'most of the time', 'sometimes' and 'rarely')
- Comments
- Standardised responses for the new version of the questionnaire

It can be seen from Figure 90 that information sharing by the GP is generally quite good, with around half of the countries reporting that information is shared at least most of the time. The country responding with 'rarely' was Romania.

Figure 90: How often information is actually shared by the GP



### How long does the transmission of this information take from GP to specialist?

Number of responses: 14/19

- Malta, Ireland and Luxembourg said that this information was unknown or not available, with Malta adding that "transmission of data hardly occurs"
- The responses for Denmark and Lithuania were unclear

Number of missing responses: 5

- This question was left blank by Bulgaria, Hungary, Finland, Greece and United Kingdom

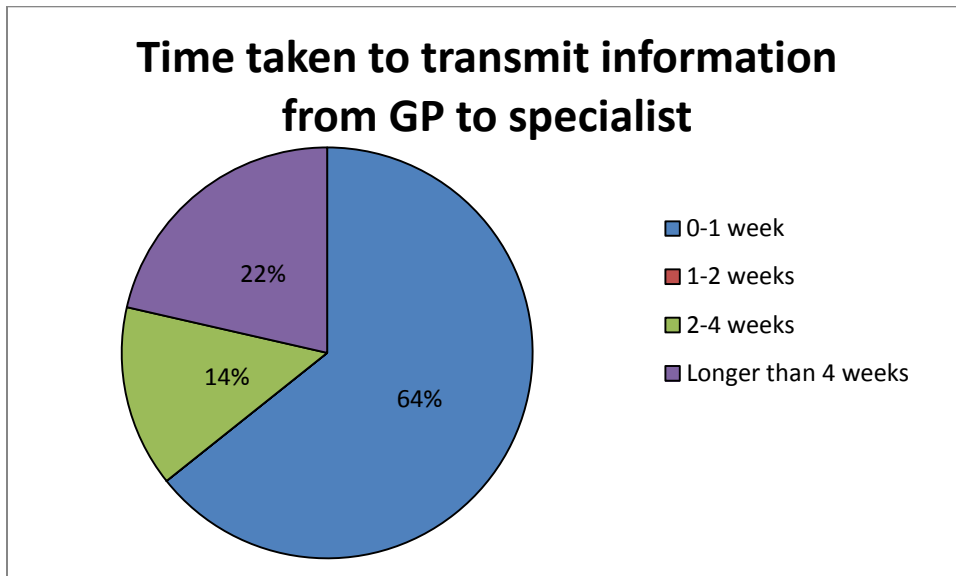
Variations in responses:

- Range of times
- Up to x days
- Time in days, weeks or months
- Descriptions of whether information is posted or sent electronically

Due to the variations between countries, the responses were grouped into different time frames, and it can be seen from Figure 91 that for around two-thirds of the countries who responded (nine out of 14), information is transmitted

within one week. Although three countries take longer than four weeks, the times reported were actually 30 days and one month, so are only just over four weeks.

Figure 91: How long it takes information to be transmitted from the GP to the specialist



### What information is the specialist supposed to give to the GP when sending a patient back?

Number of responses: 20/22

- The response for Malta was a comment rather than information
- The response for Greece said that there is “no liaising between GPs and specialists”

Number of missing responses: 2

- This question was left blank by Bulgaria and Hungary

Variations in responses:

- Descriptions
- Comments
- Standardised responses for the new version of the questionnaire

For some countries there were conflicting responses, so some information was classed as possibly being required rather than a ‘yes’. As can be seen from Figure 92, the most common information that should be provided by a specialist is the treatment proposal, with prognosis the least common. A breakdown of the ‘other’ information is provided in Figure 93.

Figure 92: Information that should be provided by the specialist to the GP

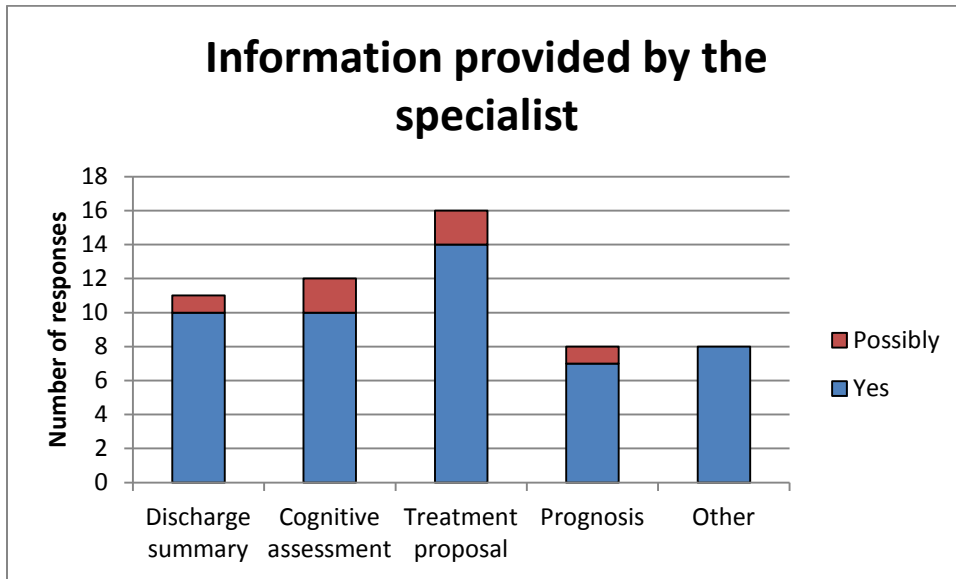
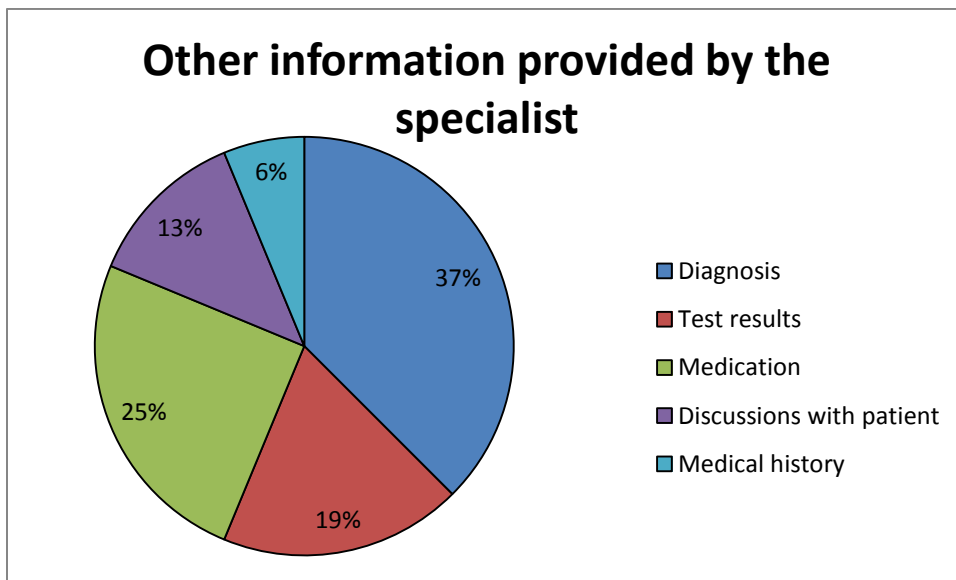


Figure 93: Other information provided by the specialist to the GP



### How often is this information actually shared specialist to GP?

Number of responses: 17/19

- The response for Malta was a comment rather than information, saying that most specialists do not contact GPs about their patients
- The response for Denmark was unclear

Number of missing responses: 5

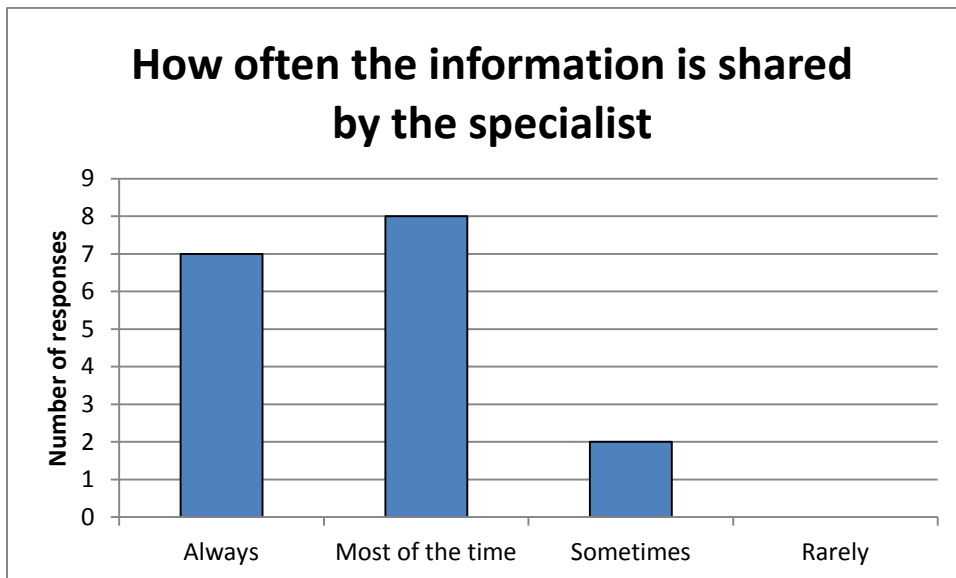
- This question was left blank by Bulgaria, Hungary, Greece, Ireland and United Kingdom

Variations in responses:

- The information provided (the original question asked for this, rather than how often. In these cases, it was compared against the information required and given an appropriate answer from the new standardised responses of ‘always’, ‘most of the time’, ‘sometimes’ and ‘rarely’)
- Comments
- Standardised responses for the new version of the questionnaire

As can be seen from Figure 94 information sharing by specialists is very good, with almost all countries saying that information is shared ‘always’ or ‘most of the time’. The two countries responding with ‘sometimes’ were Slovenia and Romania. As Romania was also the lowest country for GPs sharing information, the responses suggest that this could be an area of improvement for Romania to target.

Figure 94: How often information is actually shared by the specialist



### How long does the transmission of this information take from specialist to GP?

Number of responses: 14/18

- Malta, Ireland and Luxembourg said that this information was unknown or not available, with Malta again adding that “transmission of data hardly occurs”



- The response for Spain was unclear

Number of missing responses: 6

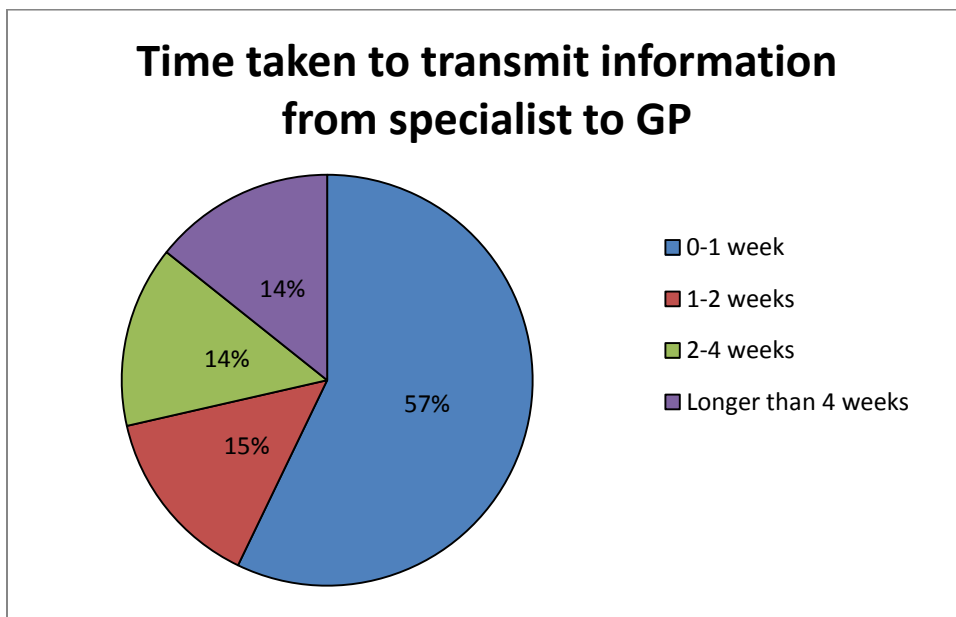
- This question was left blank by Bulgaria, Hungary, Romania, Finland, Greece and United Kingdom

Variations in responses:

- Range of times
- Up to x days
- Time in days, weeks or months
- Descriptions of whether information is posted, sent electronically or given directly to the patient/caregiver

Overall, the situation shown in Figure 95 is very similar to the transmission of information in the opposite direction, with most countries responding that information is shared within a week. Again although two countries said that it takes longer than four weeks the reported times were only slightly longer at 30 days and one month.

*Figure 95: How long it takes information to be transmitted from the specialist to the GP*



## Is there specific training and/or accreditation to enable GPs to diagnose dementia?

Number of responses: 19/22

- The responses for Slovakia, France and Denmark were unclear

Number of missing responses: 2

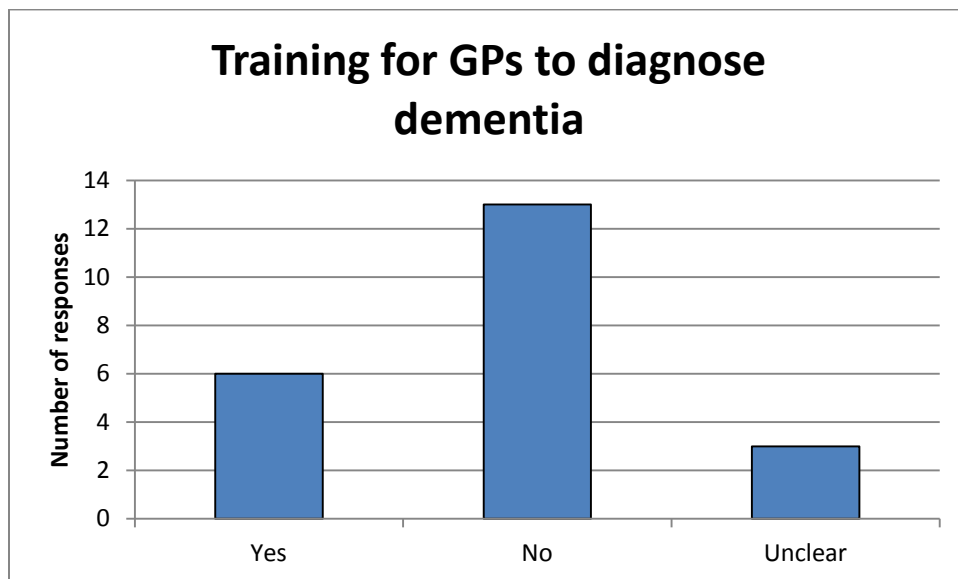
- This question was left blank by Bulgaria and Hungary

Variations in responses:

- Yes/No responses
- Descriptions
- The responses for Estonia and Lithuania were interesting, because although they both said that training was optional, Estonia responded 'yes' and Lithuania said 'no'. The viewpoints of both countries were preserved

The responses shown in Figure 96 indicate that the vast majority of countries do not have training in place to enable GPs to diagnose dementia.

Figure 96: The number of countries with training to enable GPs to diagnose dementia



## Is there specific training and/or accreditation to enable GPs to recognise the symptoms of early dementia?

Number of responses: 20/22

- The responses for France and Denmark were unclear

Number of missing responses: 2

- This question was left blank by Bulgaria and Hungary

Variations in responses:

- Yes/No responses
- Descriptions

The responses regarding training to recognise symptoms of early dementia are almost identical to those for the previous question about training to diagnose dementia, and indicate that this could be an area where most countries could make an improvement.

*Figure 97: The number of countries with training to enable GPs to recognise the symptoms of early dementia*

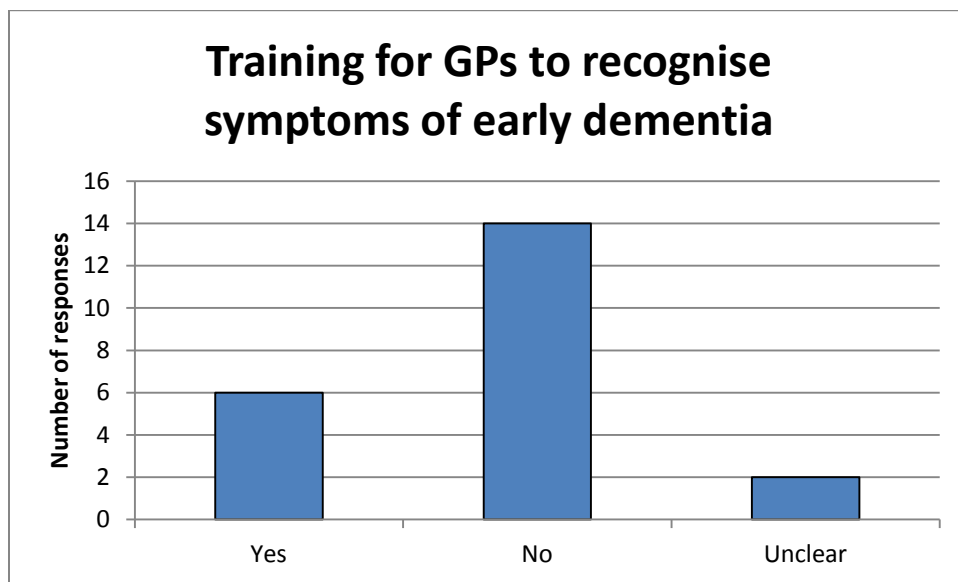
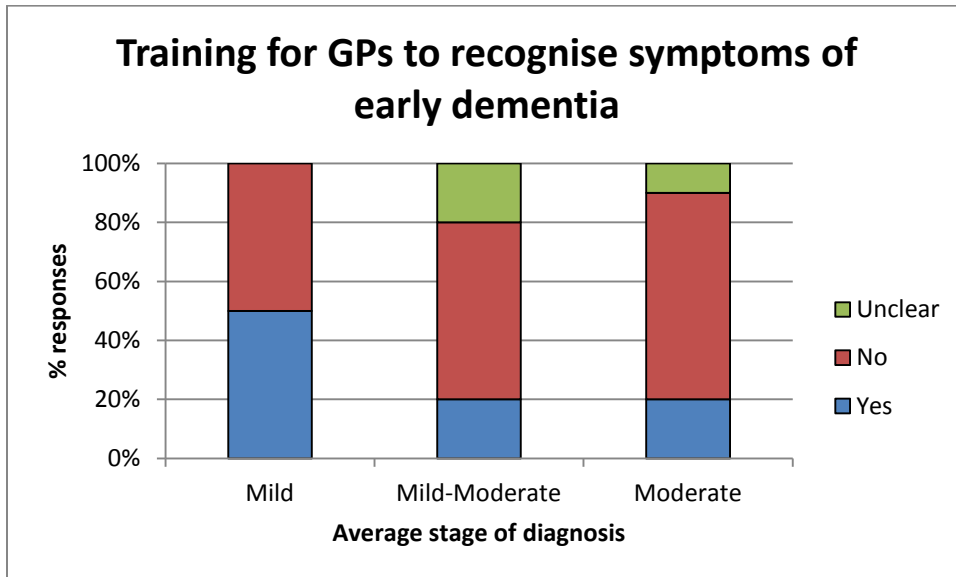


Figure 98 considers these responses based on the average stage of diagnosis in each country. It can be seen that countries which diagnose at mild stage are most likely to provide training for GPs to recognise symptoms of early dementia. Although the GPs themselves are generally less likely to be involved in the actual diagnosis, they are able to refer patients to appropriate specialists.

Figure 98: The number of countries with training to enable GPs to recognise the symptoms of early dementia, based on average stage of diagnosis



### What percentage of GPs are trained to diagnose dementia?

Number of responses: 9/20

- The information was unknown or not available for Slovakia, Estonia, Latvia, Lithuania, Denmark, Greece, Belgium and Ireland
- The responses for Sweden, Malta and Spain were unclear

Number of missing responses: 4

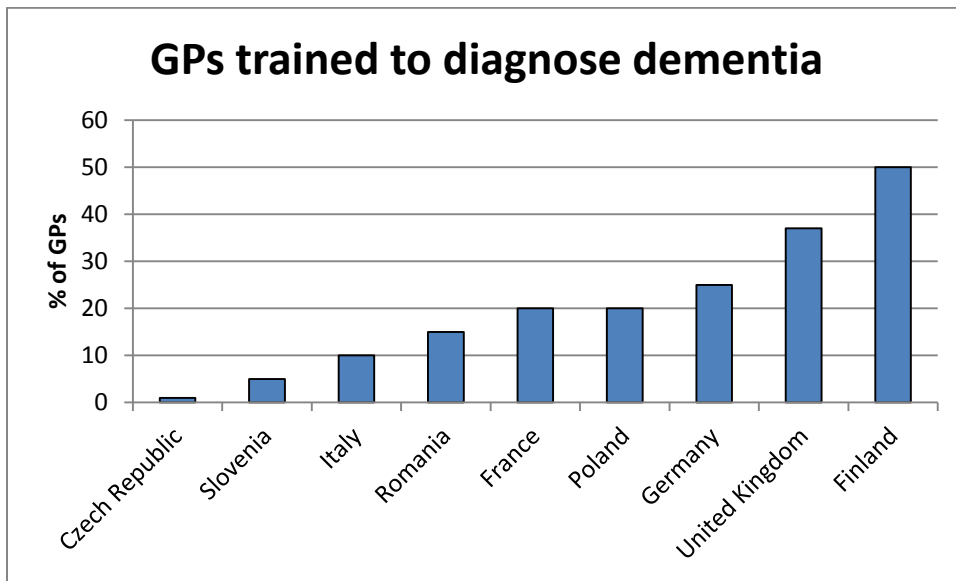
- This question was left blank by Bulgaria, Hungary, Netherlands and Luxembourg

Variations in responses:

- Range of values
- Approximate values
- Specific values
- Less than x%
- Vague number of individuals that could not be converted to a percentage

As can be seen from Figure 99Figure , the responses varied greatly between countries, ranging from 1% (Czech Republic) to 50% (Finland). This reinforces the previous results looking at whether training was provided, and shows that GPs are under-trained when it comes to dementia.

Figure 99: The % of GPs trained to diagnose dementia



### What percentage of GPs are trained to recognise the symptoms of early dementia?

Number of responses: 8/19

- The information was unknown or not available for Slovakia, Latvia, Lithuania, Greece, Belgium and Ireland
- The responses for Sweden, Denmark, Malta, Spain and France were unclear

Number of missing responses: 5

- This question was left blank by Bulgaria, Hungary, Netherlands, Luxembourg and United Kingdom

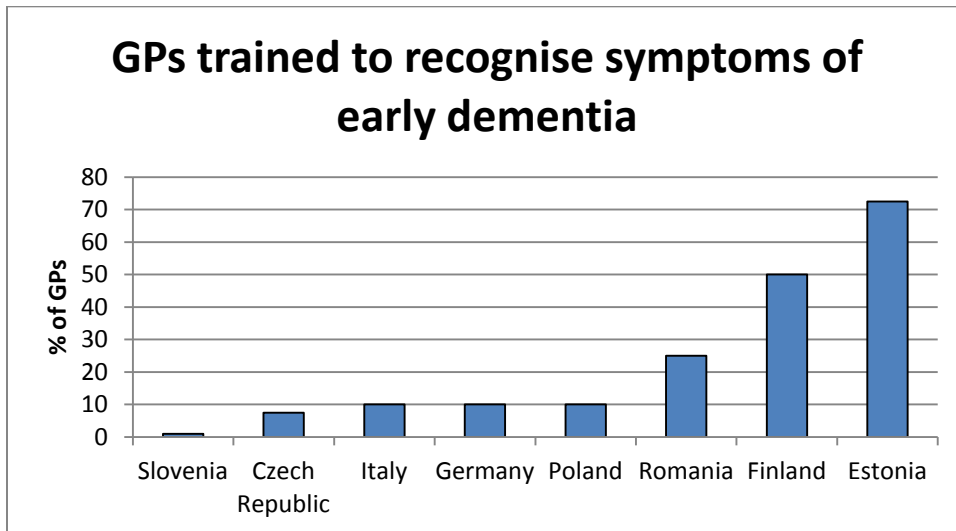
Variations in responses:

- Range of values
- Approximate values
- Specific values
- Vague number of individuals that could not be converted to a percentage

The responses were again varied, with only Estonia giving a response greater than 50%. This also shows that dementia training for GPs is an area in need of definite

improvement. The fact that many countries do not have information available about GP training is also an area for concern.

Figure 100: The % of GPs trained to recognise symptoms of early dementia



# Summary of Questionnaire Responses

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## Current practices in the European Union

### Memory testing

There appears to be some contradiction in terms of who is responsible for memory testing. Responses for one question asking about which professionals test memory indicated that it was mainly Neuropsychologists and Nurses, with Neurologists a lot less likely. Another question asked who assesses intellectual function including memory testing and got the response that it was mainly Neurologists, Psychiatrists, Geriatricians and GPs, with Neuropsychologists being less likely.

Where memory testing takes place depends to some extent on who carries it out, but the range of more specialist professions mentioned above indicates that it is more likely to be within a hospital setting. Whether this is the preferred or most appropriate setting was not assessed by the questionnaire.

The main area where there was EU-wide consensus was in terms of the tools used to assess memory. MMSE and the Clock Drawing Test were by far the most common tools, although a few others were mentioned by a handful of countries. Being the most popular tools does not necessarily mean that they are the best options available, and it should be considered whether they are sufficient or whether other tools should in fact be more widely used than they are.

### Screening services

According to the questionnaire responses, most EU countries have screening services for both dementia and Mild Cognitive Impairment. These services are most likely to be hospital-based and least likely to be in care homes. The services are mainly opportunistic in terms of who is screened.

One possible query regarding this area is what the different countries actually understand by screening services. If interpretation is different for different countries, it could potentially have an impact on the services that are actually provided. The reason for raising this query relates to the potentially contentious nature of screening services and the higher number of countries claiming to have those services in place.

## Medical imaging

Overall, the medical imaging that is actually used was quite similar to the recommendations, although there were some differences in terms of what the imaging was used for.

Younger/working age:

- MRI was the most common type of imaging
- MRI and CT scans were mainly routine, and used more in practice than suggested by the recommendations
- PET & SPECT was more for research and for specific patients, especially in practice

Pre-dementia/MCI:

- MRI was the most common type of imaging
- MRI and CT scans were mainly routine, but MRI was less routine in practice
- PET & SPECT was more for research and for specific patients, but was used less often in reality

Without obvious clinical signs:

- MRI was the most common type of imaging
- CT scans were mainly routine
- MRI was used routinely, for specific patients and for research
- PET & SPECT was more for research and for specific patients, especially in practice

With obvious clinical signs:

- MRI was the most common type of imaging
- CT scans were mainly routine
- MRI was mainly routine in the recommendations, but more for specific patients in reality
- PET & SPECT was more for specific patients and for research, especially in practice

Late stage:

- CT was the most common type of imaging
- CT scans were mainly routine



- MRI was routine and for research
- PET & SPECT was more for research and for specific patients
- MRI and PET & SPECT were less common than for other stages of dementia

The main differences between the types of medical images used are seen for patients in the late stage, where imaging overall was less commonly recommended, and CT scans were the main routine type of imaging.

One of the reasons why what was done was not always the same as what was recommended was that there is variation in resources and availability of equipment, so it is not always possible to follow the recommendations.

CSF biomarkers were not routinely measured in any country, and where they were measured it was generally for specific patients or for research.

### **Different roles**

Although there was some variation between countries, four main professions were repeatedly identified as being responsible for different tasks associated with the diagnosis of dementia, both officially and in reality. Overall, GPs, Neurologists, Geriatricians and Psychiatrists were the main professions for:

- Assessing intellectual function
- Making a diagnosis overall
- Making a diagnosis in simple cases
- Making a diagnosis in complex cases (not GPs)
- Disclosing a diagnosis
- Determining patient management strategy
- Initiating anti-dementia drugs
- Ensuring patient and carer follow-up
- Monitoring anti-dementia drugs
- Monitoring adverse reactions
- Discontinuing treatment
- Monitoring deterioration in cognitive function

This puts a lot of responsibility of GPs, especially when they say that they have not had much training around dementia.

Other professionals including Nurses, Psychologists, Neuropsychologists and Occupational Therapists were involved with:

- Assessing intellectual function
- Determining patient management strategy
- Ensuring patient and carer follow-up
- Monitoring deterioration in cognitive function

The official professions for each role and who actually performs each role in reality are generally quite close, although it is likely that more people will be involved in day-to-day practice.

The main role which showed up as being different from the rest was providing psycho-social interventions, as all professions were involved in this area. In terms of the interventions offered, the more 'concrete' ones were most common, such as information, education and social support, while Cognitive Stimulation Therapy, psychotherapy and reminiscence were least common.

There is generally a lack of clarity and consistency around advance directives. GPs and specialists are generally aware of the related legislation, and advance directives commonly cover arrangements for the future, power of attorney and aspects that require future plans. However, there is no common picture regarding who should encourage patients to design an advance directive, or who is responsible for their promotion. It is generally considered to be the role of the specialist rather than the GP, although this differed between countries.

## **Key challenges facing countries in the European Union**

### **The scale of the situation**

Having an ageing population is a common issue across the EU with around 10-20% of people being aged 65+ (6-10% are 75+ and 1.5-3% are 85+). Therefore conditions which are especially pertinent to people in this age range, such as dementia, cannot be ignored. To cope with the high proportion of older people it is necessary to have sufficient numbers of professionals, but the degree to which different roles have been established and developed depends on the country. The most widespread role appears to be the GP, with 3.47 GPs for every 1,000 people aged 65+ (one GP per 290 people aged 65+). This is followed by Psychiatrists (0.61 per 1,000 or one per 1,640 people aged 65+), Neurologists (0.35 per 1,000 or one per 2,860 people aged 65+), Geriatricians (0.09 per 1,000 or one per 11,100 people aged 65+) and Old Age Psychiatrists (0.02 per 1,000 or one per 50,000

people aged 65+). From this it can be seen that the more specialised professions are (unsurprisingly) least widespread, and so could be put under greater pressure in the future as the number of people aged 65+ increases.

With the relatively low numbers of professionals it perhaps should not be unexpected that a large majority (40-60%) of dementia diagnoses are missed, and when a diagnosis is made it tends to be when the dementia is already at a moderate stage. In some countries, diagnosis does take place when the dementia is still mild or mild-moderate, but ideally this should be the case for all countries. Almost all countries have run dementia awareness campaigns for both professionals and the general public, so it is hopeful that the situation will improve with doctors spotting symptoms of dementia earlier and patients being more aware of dementia and seeking help sooner.

### **Service provision**

Although it can be dependent on the country, the majority of professionals (Neurologists, Geriatricians, Psychiatrists and Old Age Psychiatrists) are hospital-based. In most countries people working in these professions are based in the community setting as well, but to a lesser extent. The location of these professionals could potentially limit access to the services they offer, not just in terms of whether they are easier to get to, but also in terms of whether people are more or less likely to use a service if it is in a hospital rather than a community environment.

One of the main services considered by the questionnaire is memory clinics, with nearly every country reporting that they have their own memory clinics. However, the picture is not as positive as it appears, with memory clinics generally not considered to be widespread, and each clinic having to cater for anywhere between 24,000 and 1.2 million people aged 65+. There is also variation between countries in terms of memory clinic coverage, with the EU median being approximately 50% coverage by memory clinics. In addition to memory clinics, most countries also offer memory services. While the number of people aged 65+ per memory service is similar, memory services are generally considered to be even less widespread than memory clinics. However, the EU median is over 60% coverage, which does not appear to support this view. Overall, the opinion in most countries is that memory assessment is not accessible to all people.

A particular gap that was identified by the questionnaires involved younger people with dementia, as 73% of countries said that they do not have specific centres for younger patients. This is therefore an area to be addressed, but it should be

investigated whether younger people need specific centres or whether making suitable services available at memory clinics would be appropriate.

By improving service provision and accessibility, it may or may not be possible to reduce waiting times for specialist assessment, which is currently within eight weeks for 81% of cases. The danger is that if services do not improve but more people are referred for diagnosis, then the existing services become overloaded and waiting times increase.

### **Training and support – in particular from a GP perspective**

When it comes to dementia diagnosis there appears to be some confusion over the role of GPs, and this is not helped by the fact that in most countries there is a lack of policies to improve diagnosis, and a lack of diagnosis guidelines in approximately one-third of countries. In addition, hardly any countries have overarching dementia pathways in place. Without these elements it is difficult for patients and professionals to understand where they fit into the dementia journey, and for professionals such as GPs to know what their role is. Developing such information would therefore be important to help different groups and services fit together and potentially make the diagnosis process feel less disjointed.

The guidelines and policies would help to support GPs in their role, especially as approximately 70% of GPs say that they have a lack of specialist training to diagnose dementia and recognise symptoms of early dementia. This lack of training, combined with a lack of understanding or clarity regarding their role, could have an impact on the relationship between GPs and specialists. There is some disparity concerning information sharing between these two parties, with information not necessarily being shared as and when required. The transmission of information appears to be better from specialists to GPs than from GPs to specialists, although it should be noted that the questionnaires were more likely to be completed by people in roles that would count as specialist rather than by GPs.

Implementing appropriate guidelines could therefore be beneficial in a number of areas as it would support GPs, and other professionals, in terms of knowing what their role is within the wider dementia pathway and within the diagnosis process, making information exchanges more valuable. Underpinning this would be GP training, which would help GPs to better understand dementia and the diagnostic process, and enable them to appreciate the importance of their relationship with specialists.

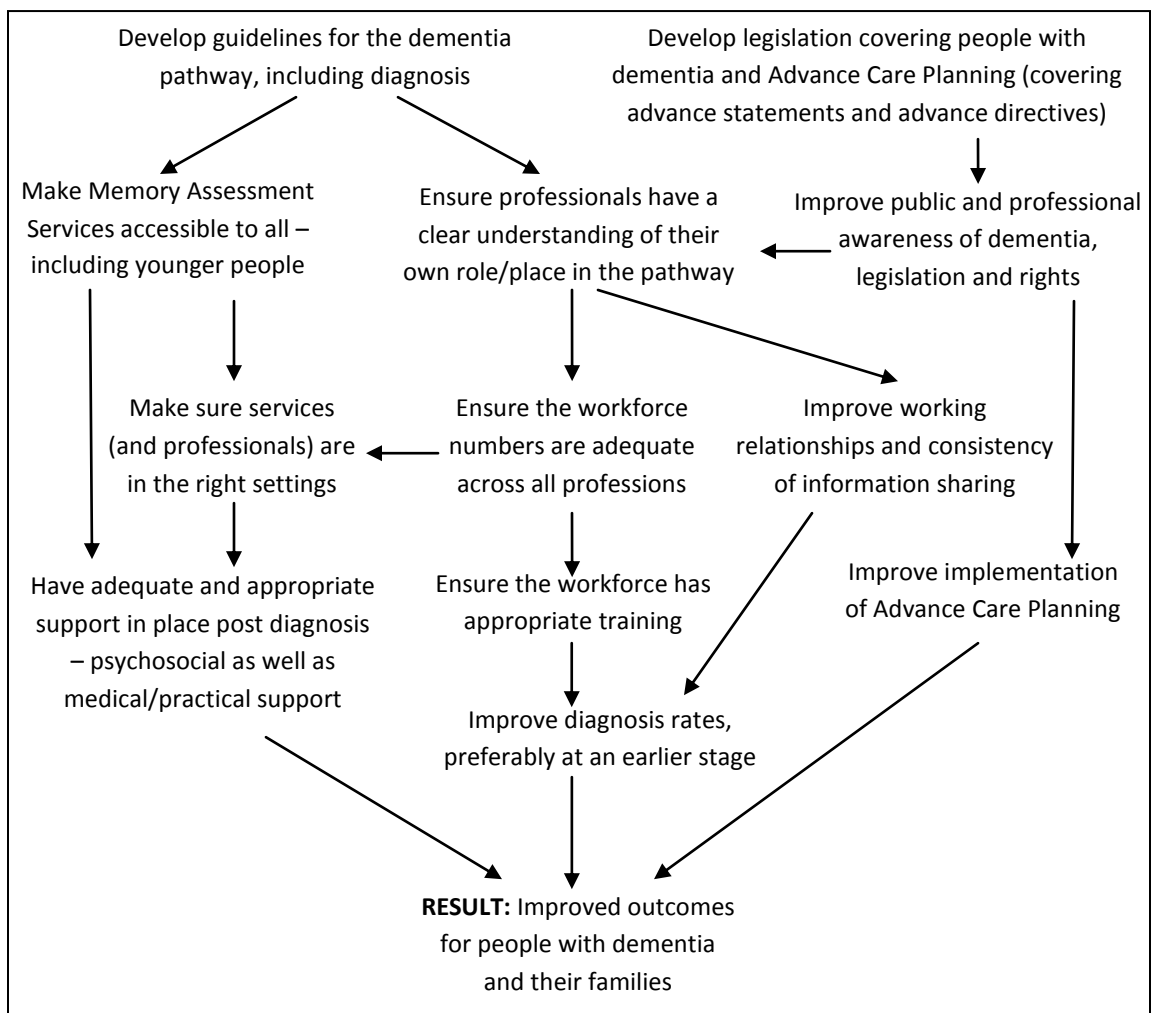
## **Legislation**

Legislation in general for people with dementia appears to be quite poor. Approximately one-third of EU countries do not have legislation to protect people with dementia, and nearly 50% do not have legislation for advance statements and directives. Even where legislation exists, it is not consistently implemented/supported/promoted. For example, more clarity is required regarding who is responsible for promoting advance directives, and there needs to be more awareness of them and what they relate to. Having suitable legislation is almost irrelevant if people do not actually know about it or do not use it properly.

# Proposition – Recommendations and Tools

Based on the key challenges facing countries in the EU as identified in the previous section, a number of recommendations have emerged. These recommendations should not be seen as stand-alone points, but as being interconnected and interdependent, as indicated by the way they are linked in Figure 101. For example, the ability to ensure that professionals have a clear understanding of their role and place in the dementia pathway will be significantly aided by having clearly developed guidelines for the pathway in place.

Figure 10111: Interconnected recommendations



The mechanisms and tools for implementing these recommendations are not described here as they are likely to differ between countries, especially where the existing situations are different, as this means that different countries are working from different starting points. For example, building on and developing existing services may require a different approach and set of tools to starting up a new service from scratch.

It is worth noting that although the recommendations apply to all EU countries, it is not actually necessary for the final situation to be consistent across Europe. It is much more important to have consistency and understanding within each country, especially in terms of what roles are carried out by whom, and what tools, processes and images are used when assessing and treating different groups of patients.

## Summary of Recommendations following validation

The recommendations from the literature were validated through a series of workshop presentations, written and email responses with people living with dementia, family carers and professionals. Taken together, the recommendations from the literature and the current reported situation across the EU have been synthesised into a series of final recommendations that can be utilised across different countries. Recommendation 1 is concerned with the fundamental principles on which underpin all further recommendations in this area.

### 1. The diagnosis of dementia should be person-centred and actions associated with it should be based on the following principles:

- **Timely** diagnosis of dementia should be available to all citizens who require it **and accessible** to all sections of the community at a stage when people first notice changes in cognitive function;
- **Decreasing fear and stigma** about dementia are necessary pre-cursors for increasing the numbers of people coming forward for diagnosis;
- The **rights and wishes** of the person with suspected dementia should be paramount in engaging with the assessment process used to achieve a diagnosis
- Giving and receiving a **diagnosis of dementia is a key intervention** in the complex adjustment process to living with dementia. The needs of **the person and their family/significant others** are central to assessment, diagnosis and post-diagnostic interventions.

**2. Case finding can be an effective process to identify people to Increase diagnosis in circumstances where there are services available that will benefit the person and their family**

Targeted or opportunistic case finding within primary care, acute hospitals or care homes should be undertaken and steps taken to ensure that services and support is available to bring benefit to the person and their family.

General population screening is not recommended until there is better evidence of the reliability of screening alongside ways of preventing or delaying dementia.

**3. The diagnostic process should support positive adjustment, provide an evidence based assessment and enable care planning to take place following diagnosis**

The diagnostic process is managed in a way that supports good adjustment to the news. This includes:

- a) The provision of pre-assessment counselling which should address:
  - i. Provision of information concerning the diagnostic assessment process;
  - ii. Possible outcomes of the assessment process;
  - iii. Promoting rights to choice and control over whether to go forward for diagnosis.
- b) Where and who should be present for diagnostic feedback;
- c) What interventions can be offered following diagnosis;
- d) A sensitively delivered process of disclosure of the diagnosis;
- e) The provision of information and interventions post diagnosis.

Timely diagnosis covers a sequence of four stages, each of which may be delivered by any properly trained professional but needs to be coordinated at the individual patient level:

- a) Initial detection of cognitive difficulties and other symptoms indicative of dementia;
- b) Assessment to decide whether symptoms are due to dementia or not;
- c) If dementia is present, to achieve diagnosis of the cause and relevant co-morbidities;
- d) Care planning to address current and future needs.

Recent clinical criteria for diagnosis of dementia syndrome and its subtypes are used in clinical practice, recognising that this is a changing area and that further validation and



revisions will occur (McKhann, *et al.* 2011; Gorelick, *et al.* 2011; Rascovsky, *et al.* 2011; Gorno-Tempini, *et al.* 2011; Macijauskiene & Lesauskaite, 2012; Goetz, Emre & Dubois, 2008; Benisty, *et al.* 2008).

Systems need to be in place so that professionals stay up to date with the clinical criteria for diagnosis

Biomarkers (CSF and functional neuro-imaging) are recommended only for use in research centres and not in general clinical practice.

**4. Diagnosis of complex presentation of dementia is made in as timely a fashion as for simple cases**

Particular skills are required where people have a young age of onset, have pre-existing health difficulties or intellectual disability.

In these situations case finding, assessment processes and interventions are utilised that are relevant to the particular needs of the population.

**5. A consensus is required on how early cognitive changes at time point 2 (currently known as Mild Cognitive Impairment) are to be responded to in clinical practice**

Proposed changes to diagnostic classifications, should clarify how early cognitive changes are defined and responded to in clinical practice. At the present time, the label MCI is from the public health point of view a research diagnosis area.

When people are informed that they have early cognitive changes, advice and support should be given alongside clear systems for monitoring and follow up.

**6. Workforce development is required across all levels to facilitate timely detection, evidence based assessment and diagnosis and to facilitate good adjustment.**

When planning national strategies for dementia, workforce and service development issues are taken into account

Family doctors and their colleagues working in Primary Care, Care Homes and Acute General Hospitals should receive education and learning, and evidence based decision support toolkits to assist them in their role in detection of dementia.

Systems are developed to support detection at an early stage by family doctors including shared care with specialists, guidelines in detection, education and case management.

Specialist services at the secondary level can improve timely diagnosis to good effect but there are challenges to implementing this model where there is a lack of specialist expertise and a dispersed rural population.

Workforce development strategies are in place for the wide range of health, social care and community staff involved to enable these staff to facilitate good adjustment in those receiving a diagnosis and their families.

These recommendations were subsequently further developed to provide policy makers, practitioners, governments and the general public with key statements and associated strategic actions for all six areas identified in the recommendations. These are presented below.

# Key Recommendations

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## Overarching recommendations

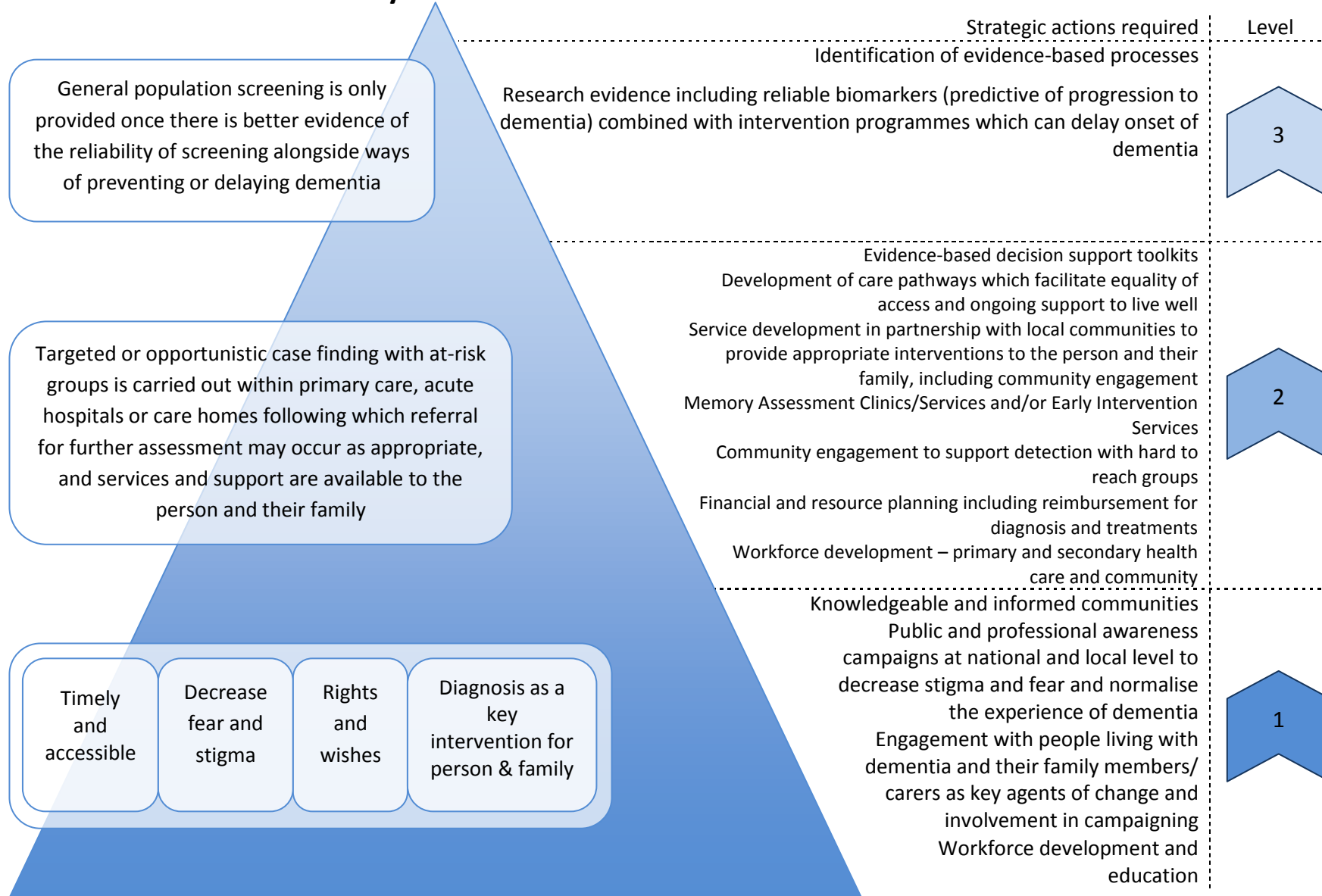
1. The diagnosis of dementia should be person-centred and actions associated with it should be based on the following principles:
  - **Timely** diagnosis of dementia should be available to all citizens who require it **and accessible** to all sections of the community at a stage when people first notice changes in cognitive function;
  - **Decreasing fear and stigma** about dementia are necessary pre-cursors for increasing the numbers of people coming forward for diagnosis;
  - The **rights and wishes** of the person with suspected dementia should be paramount in engaging with the assessment process used to achieve a diagnosis
  - Giving and receiving a **diagnosis of dementia is a key intervention** in the complex adjustment process to living with dementia. The needs of **the person and their family/significant others** are central to assessment, diagnosis and post-diagnostic interventions.

In the remainder of this document the above principles will be summarised as:

1. Timely and accessible
2. Decrease fear and stigma
3. Rights and wishes
4. Diagnosis as a key intervention for person & family

This section details the set of recommendations developed from the work carried out within ALCOVE Work Package 5. The recommendations relate to a number of key areas identified by the work and are presented in the form of pyramids. The recommendations at the foot of the pyramid are fundamental to each key area and represent a baseline standard of care, with subsequent levels covering more sophisticated recommendations. The text accompanying the pyramids details the minimum strategic actions that are required at each level to achieve the desired standard of care.

## Recommendations for timely detection



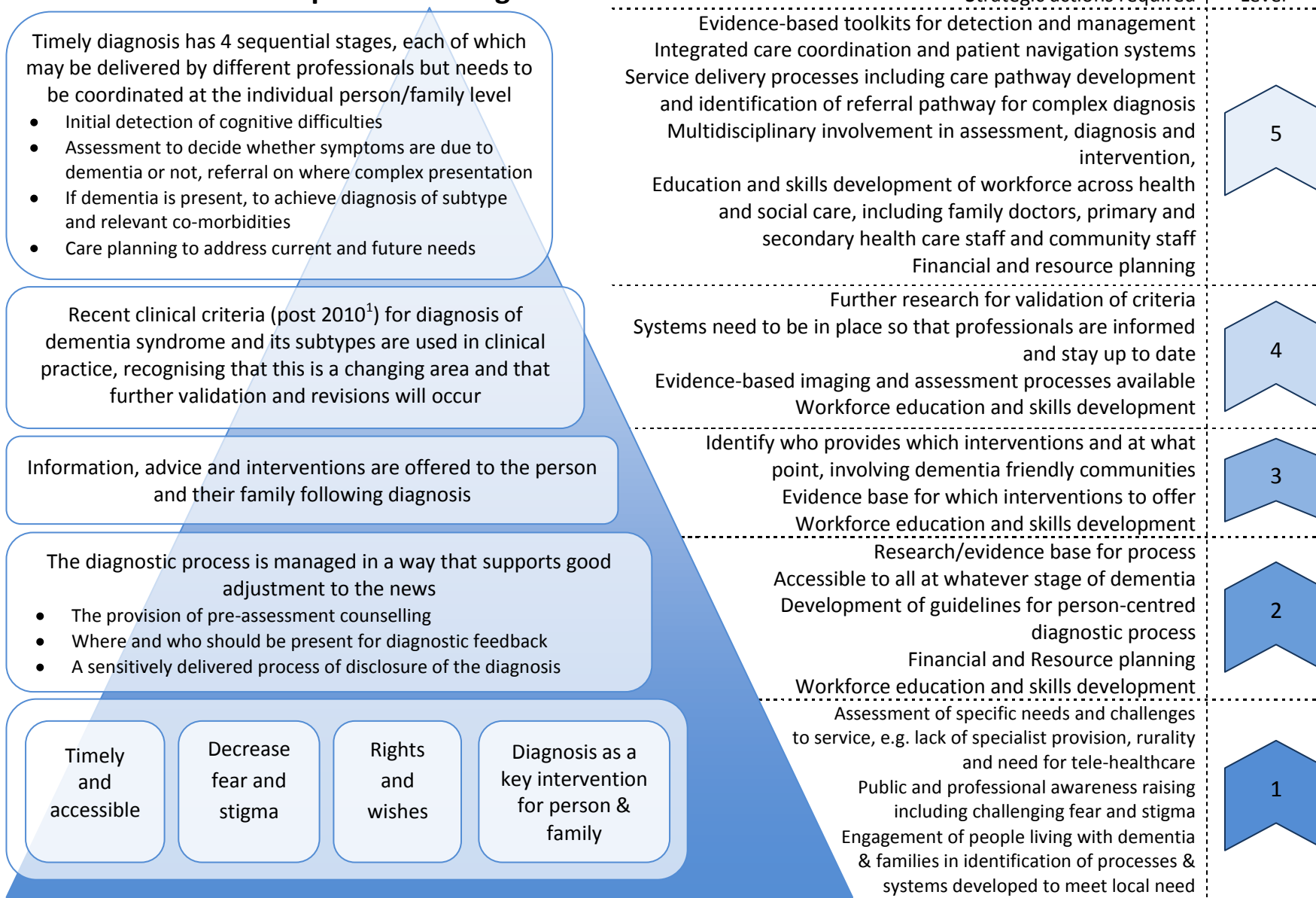
## **Questionnaire findings relating to timely detection**

Most countries in the European Union currently diagnose dementia when it has already reached a moderate or mild-moderate stage, with only a few countries diagnosing people when the dementia is at a mild stage. The majority of countries claim to have screening services in place for both dementia and Mild Cognitive Impairment, and countries that diagnose dementia at earlier stages are more likely to have screening services.

Currently, screening services are most often located in hospital settings, with the lowest levels of screening found in residential care. In countries diagnosing dementia at a mild stage the screening is more frequently targeted towards general or at-risk populations, while countries diagnosing at moderate stage are most likely to carry out opportunistic screening.

It is not clear whether different countries are using the term ‘screening services’ to mean the same thing. In order to develop screening services, a clear and common definition of what these services are and what they entail needs to be established, together with their place within the dementia pathway. This will support the development of services that are implemented in a consistent manner, integrated with the wider dementia pathway – including workforce training, interventions and support – and take into account the broader impact of an earlier diagnosis.

## Recommendations for process of diagnosis



(<sup>1</sup>McKhann, *et al.* 2011; Gorelick, *et al.* 2011; Rascovsky, *et al.* 2011; Gorno-Tempini, *et al.* 2011; Macijauskiene & Lesauskaite, 2012; Goetz, Emre & Dubois, 2008; Benisty, *et al.* 2008)

## **Questionnaire findings relating to process of diagnosis**

Across the EU, most countries have been trying to raise awareness of dementia through communication campaigns, with the majority being aimed at both the general public and professionals. These campaigns will hopefully encourage people to seek help sooner if they are concerned about their memory. They therefore need to be backed up by a robust diagnosis process. Approximately two thirds of countries have national official guidelines in place to support diagnosis, and these tend to be the countries that are more likely to diagnose dementia earlier.

The diagnostic process consists of a number of different elements and four main professions are often involved at each stage: family doctors, Neurologists, Geriatricians and Psychiatrists. This raises challenges due to relatively low numbers of these professionals working across the EU. For example, on average for every 1000 people aged 65+ there is less than one Neurologist, 0.5 Geriatricians and one Psychiatrist in post. The situation is slightly better for family doctors, with between two and seven GPs for every 1000 people aged 65 or over.

### ***Pre-diagnosis***

The most widely used tools for detecting early diagnosis are the Mini Mental State Exam and Clock drawing tests. In terms of medical imaging, CT and MRI scans were most common and more likely to be used routinely, with PET & SPECT used more for research purposes or with specific patient groups.

A key part of the diagnosis process is the information exchange between professionals, with two thirds of GPs sharing the required clinical history and signs and symptoms information with specialists, generally within one week, and over half of specialists sharing treatment proposal and cognitive assessment information, again generally within one week. Specialists were considered to be better at sharing information overall.

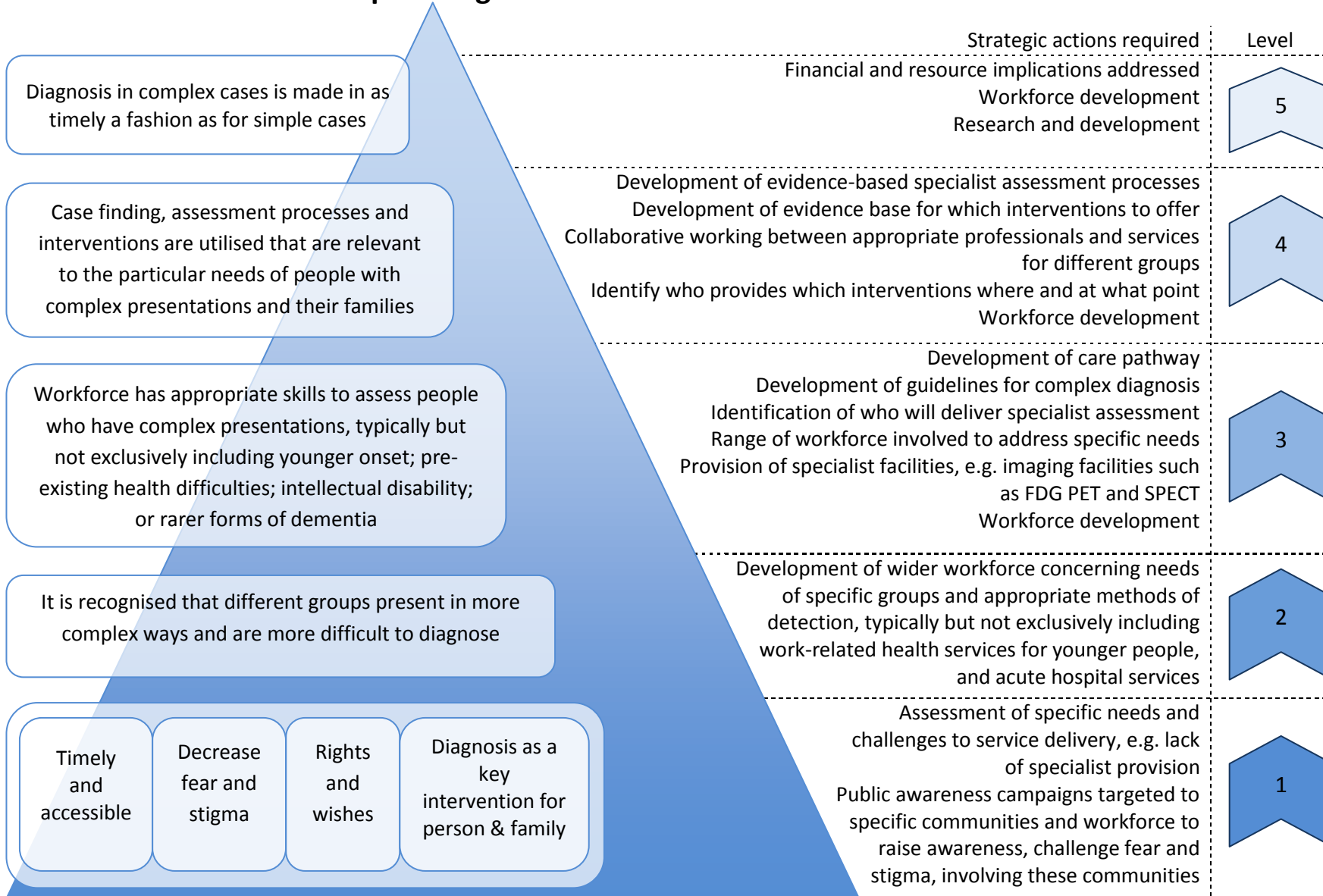
All but one of the responding EU countries have Memory Clinics. However, coverage varies considerably between countries and on average there are 200,000 people aged 65+ for each clinic. Most countries also have additional memory services, but these are even less common and support almost twice as many people.

### ***Post-diagnosis***

Following diagnosis, many countries offer a range of psychosocial interventions. Provision varies considerably, with 61% of countries offering information about dementia and only 11% offering creative therapies. These interventions often involve a wide range of professionals, rather than just the four main professions mentioned previously, indicating the need for good communication and understanding between professionals. Nearly two thirds of countries have legislation in place to protect vulnerable adults including people with dementia, with countries that diagnose earlier being slightly more likely to have such legislation. Over half of the countries questioned have legislation for advance statements and advance directives, although this was less likely to be the case in countries that diagnose at the moderate rather than mild stage.



## Recommendations for complex diagnosis



## **Questionnaire findings relating to complex diagnosis**

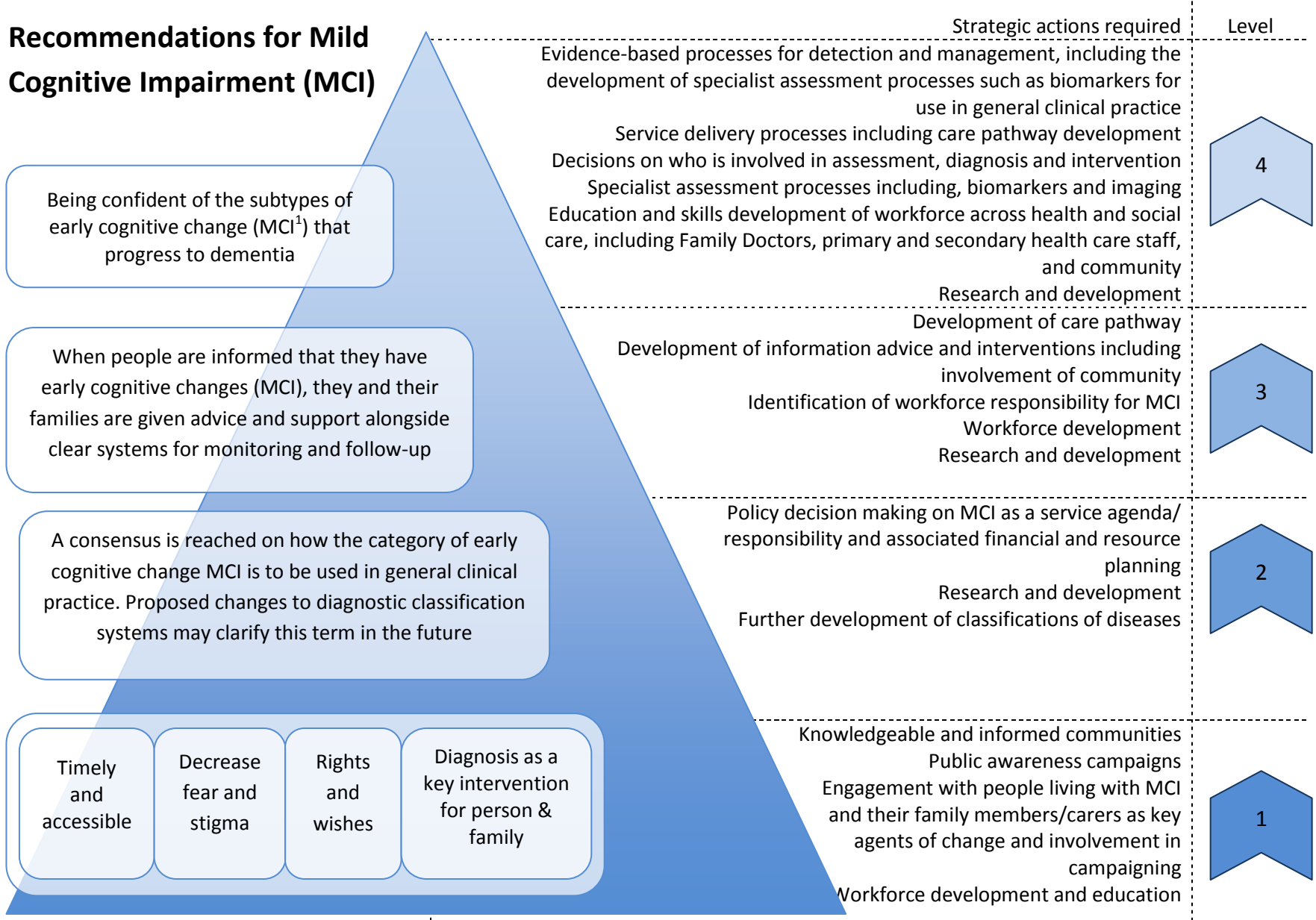
All of the findings from the previous section relating to the process of diagnosis are also relevant to complex diagnosis. Only a few aspects of the questionnaire focussed specifically on complex diagnosis and/or younger people, but it is hoped that at least some of the activities known to be taking place within different countries cover complex diagnosis, e.g. awareness campaigns targeting specific communities, or psychosocial interventions incorporating cultural awareness.

One area where complex diagnosis does not appear to be particularly well catered for is service provision. For example, the majority of countries said that they do not have specific centres for younger people of working age with dementia, suggesting that the workforce in more general services will need to be trained appropriately to ensure that the needs of younger people are met.

In terms of making a diagnosis in complex cases, there is recognition that it requires more specialist knowledge, with family doctors generally not being involved – although they are in simple cases. Complex diagnoses are usually carried out by Neurologists, Geriatricians and Psychiatrists.

Although it is difficult to tell from the more general questionnaire responses, it seems likely that complex diagnosis is an area where improvements can be made.

## Recommendations for Mild Cognitive Impairment (MCI)



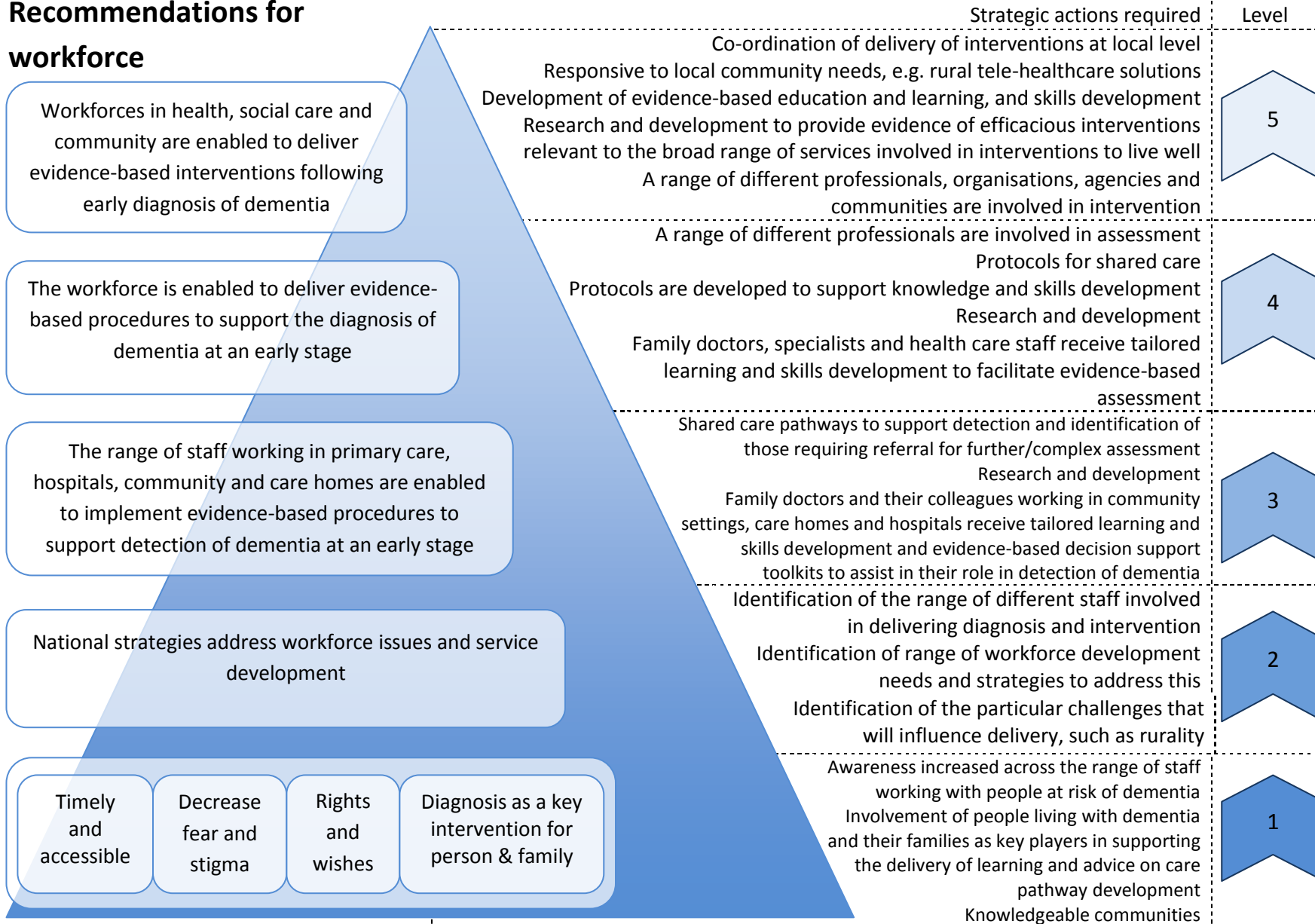
### **Questionnaire findings relating to MCI**

As with complex diagnosis, many of the previous comments around the process of diagnosis are also relevant to MCI. There were only a few areas in the questionnaire focussing specifically on MCI, so additional comments are limited.

It is possible that at least some of the activities known to be taking place across the EU will include MCI and that in the two thirds of countries with national guidelines for diagnosis, those guidelines will cover MCI. Also, although few countries have dementia pathways at present, when such pathways are developed they will need to include MCI as well as dementia.

As the level of missed dementia diagnosis across the EU is currently 40-60%, diagnosis as a whole needs to improve significantly before detection of MCI can be properly addressed.

## Recommendations for workforce



## **Questionnaire findings relating to workforce**

Most countries have campaigns to raise awareness of dementia aimed at both the general public and professionals, which should help professionals to recognise the importance of diagnosing dementia in a more timely fashion. Although two thirds of countries have national guidelines for diagnosis, professionals need to know where they fit and what their role is with respect to those guidelines. The same is true for overall dementia pathways, although only a few countries have these in place at present.

Four main professions – family doctors, Neurologists, Geriatricians and Psychiatrists – are involved at every step of the diagnosis process, so they need to know what is expected of them at each stage. Other professionals also need to know how they are expected to work with and support these four main groups, indicating that communication and joint working is key to making the diagnosis process work for the person with dementia and their family.

The workforce in general, and particularly family doctors and specialists, need to have a wide range of information regarding dementia, or at least have sufficient awareness of different areas, such as legislation on advance statements and advance directives. One area where improvements could be made is training for family doctors. Most countries do not have training and/or accreditation to enable them to diagnose dementia or to recognise the symptoms of early dementia, and consequently less than half of family doctors are trained in these areas.

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