

TIMELY DIAGNOSIS OF DEMENTIA



*Professor Brooker, Dawn; La Fontaine, Jenny; Dr Evans, Simon; Bray, Jennifer - Association for Dementia Studies, University of Worcester;
Dr Saad, Karim - Department of Health, England*

“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” [1].

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AUTHORS OF SECTION 5 OF PROGRESS ON THE FRENCH NATIONAL PLAN: Benoit Lavallart, MD, Project Manager, Steering Committee National Alzheimer Plan - Geriatrician & Public Health physician, France; Sandrine Lemery, Project Manager, Steering Committee National Alzheimer Plan - Actuary & General engineer of "corps des mines" France; Florence Bonte – MD, Geriatrician, France; Armelle Leparre-Desplanques, MD, PhD, Head of department Pilot Programmes & Clinical Impact - The French National Authority of Health, France; Nathalie Riolacci-Dhoyen, MD, Adjoint, Pilot Programmes & Clinical Impact - The French National Authority of Health, France.

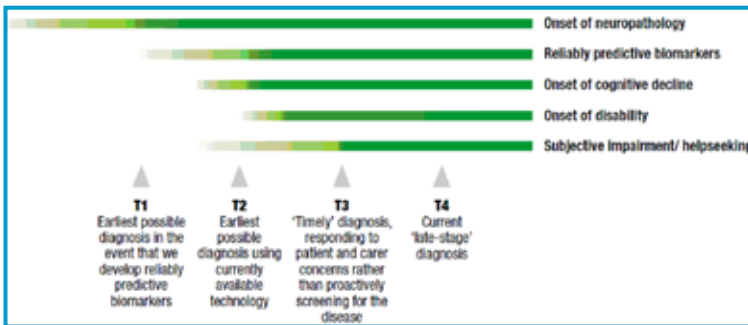
ALL SURVEY RESPONDENTS: Alfredo Antiguiedad; Jennifer Bray; Dawn Brooker; Maria Chmelova; Ann Coyle; Maria Cunderlikova; Teresa Di Fiandra; Simon Evans; Inaki Fernandez Manchola; Manuel Fernandez Martinez; Lutz Froelich; Luis Galdos; Jakub Hort; Peter Johannsen; Janos Kalman; Alicja Klich-Raczka; Dorothee Knauf-Hubel; Ales Kogoj; Liga Kozlovska; Pierre Krolak-Salmon; Vladimirs Kuznecovs; Jenny La Fontaine; Benoit Lavallart; Jan Lehotsky; Ülla Linnamägi; Pablo Martinez-Lage; Denisa Mikusova; Noel Mulvihill; Marian Nagy; Ruiz Ojeda Javier; Alessandro Padovani; Ieva Paegle; Galina Paeva; Magdolna Pakaski; Sakka Paraskevi; Vinciane Quoidbach; Daiva Rastenyte; Philippe Robert; Karim Saad; Charles Scerri; Katerina Sheardova; Gorazd B. Stokin; Catalina Tudose; Peter Turcani; Juan M. Uterga; Martin Valis; Nicola Vanacore; Frans Verhey; Matti Viitanen; Martin Vyhnalek; Gunhild Waldemar; Anders Wimo; Daina Zepa.

ASSOCIATED PARTNERS: Department of Health, UK; Athens - Association of AD and Related Disorders (AAADR), Greece; Riga Centre of Psychiatry and Addiction Disorders (RPNC), Latvia; Lithuanian University of Health Sciences (LUHS), Lithuania; Institute of Neuroimmunology of Slovak Academy of Sciences (NIU SAV), Slovakia; Fundación Vasca de Innovación e Investigación Sanitarias & Agencia Vasca de Evaluación de Tecnologías Sanitarias (BIOEF-OSTEBA), Spain; Karolinska Institute (KI), Sweden.

Method, questionnaires and analysis are developed in the WP5 Report: Timely diagnosis of dementia – www.alcove-project.eu

Research highlights that many people never receive a diagnosis of dementia and 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 [2, 3]. Up to 28 of 36 million people living with dementia world-wide have not received a diagnosis, limiting their access to treatment, information and care [3]. Some countries have set targets within their dementia strategies to improve early diagnosis rates. However, it is necessary to define clearly what is meant by early as opposed to later diagnosis particularly given such issues as the current debate concerning diagnosis and interventions in the prodromal (pre-clinical) phase of Alzheimer’s disease. Prince *et al.* [3] usefully propose a four stage timeline of disease progression (Figure. 1) which is how the evidence is structured.

Figure 1. The four-stage timeline of disease progression (Prince et al. [3])



However, for the purposes of public health, it should also be recognised that:

- T1 is an area of long term research,
- T2 is an area of short term research for possible diagnosis of Early Cognitive Changes/Mild Cognitive Impairment (MCI),
- **T3, as timely diagnosis, is the priority area to be achieved for dementia diagnosis,**
- **T4 is a late stage diagnosis area to be decreased in favour of T3.**

The aim of this chapter is to present a brief overview of the in-depth evidence from two pieces of work:

1. A critical literature review of the diagnosis of dementia including screening
2. A questionnaire survey of existing diagnostic systems in EU Member States

This evidence was synthesised to formulate recommendations for improving early diagnosis, both in ambulatory and in nursing home settings, which could be utilised by policy makers and influencers across the EU. These recommendations are presented as classical text as well as strategies for health policy in the form of pyramids.

METHOD

LITERATURE REVIEW

An initial literature search on definitions of dementia diagnosis; covering screening, practice guidelines, economic costs, and primary and health care utilising Medline and PubMed provided 1,855 abstracts plus 20 government policy documents from the EU and beyond. In order to provide evidence-based recommendations on the process of diagnosis, searches were also undertaken in Psychinfo, Psycharticles and Cinahl along with hand searches of relevant journals which generated a further 1,943 abstracts. Evidence concerning technical issues of diagnosis (e.g. classifications and testing procedures) and the care and support processes associated with diagnosis were assessed. The literature review was structured in consultation with ALCOVE partners and utilising the expertise of an external reference group.

Over 200 references were included in the critical literature review. The review consisted of sections focusing on issues of diagnosis at T1, T2, T3 and T4 [3] under the following headings:

- Differential diagnosis
- Diagnostic Classifications
- Criteria for diagnosis in each of the diagnostic subtypes
- Who presents at each stage and what they present with?
- Who do they present to?
- How long before presenting?
- What process should be delivered and by whom
- What are the key challenges?
- What are the benefits/drawbacks of diagnosis at this stage?

The progress of both dementia strategies for France and England on early diagnosis was also considered. Detailed recommendations were made at the end of each section within the literature review and a shorter recommendation list was

developed through five phases of iteration with people living with dementia, family carers and wide range of health and social care professionals.

ALCOVE QUESTIONNAIRE SURVEY

The questionnaire survey was sent to all 27 EU countries via five regional coordinators. It covered data about the age profile of the country and the numbers of health care professionals; who makes the diagnosis and how; what happens in practice as compared to official guidelines; legislation; access to specialist services and relationships between family doctors and specialists. The questionnaire was produced as a Word document and subsequently made available as an on-line survey. Following significant follow-up, responses were received from 24 countries (a response rate of 89%), although many questionnaires had incomplete sections. The questionnaire results were considered separately for each of its six sections. The analysis methods used varied depending on the individual question and the nature of the responses.

RESULTS

LITERATURE REVIEW

Undertaking a conclusive review of the literature in early diagnosis and dementia required that both the technical aspects of diagnosis and the processes associated with it were addressed, as both are necessary to facilitate a depth of understanding. The complexity of bringing together these bodies of evidence became apparent, not least because evidence concerning technical aspects of diagnosis has a significant focus on developing our understanding of the causation, prevention and treatment of dementia and is thus largely addressing diagnosis at T1 and T2. However, evidence concerning the care and support of people already living with dementia and their families has a greater focus on those who have already developed clinical signs, so will primarily be at T3 and T4. Consequently, it was necessary to consider evidence concerning advances in diagnosis; even though it might not impact practice now; in addition to a review of current evidence concerning early diagnosis and intervention.

- **Research categories at T1 and T2:** Recent advances in the technical aspects of diagnosis include the adoption of a life course perspective for the risk of developing dementia (Figure 1). These advances have prompted considerable expansion in research exploring enhanced methods of detecting and intervening at T1, specifically in the pre-clinical phase of Alzheimer's Disease (AD) and vascular dementia (VaD) [3], to prevent or delay onset [4]. This challenges what is meant by an early diagnosis. In recent years such research has advanced early detection in developing biomarker tests which, for example, measure tau protein and amyloid-beta levels in cerebrospinal fluid [5]. Currently biomarker usage is restricted to research and is not recommended for clinical practice. Further research is required to establish their ability to predict progression to dementia [3, 6, 7]. The Dubois research criteria [8] for AD recommends the use of biomarkers as part of the assessment, but has not yet been evaluated for use in clinical practice [9].

These advances have generated debate concerning at what point diagnosis should occur, and whether population screening is therefore desirable. This wider debate will continue as new evidence emerges. However population screening is not currently recommended for a number of reasons:

1. The efficacy of biomarkers and other tests at this early stage is not clear;
2. Although clinical trials are currently ongoing to deliver interventions which may delay or prevent the onset of AD or VaD [10, 11, 12], results determining the efficacy of these interventions will not be available for some time;
3. While screening for dementia might be acceptable in the future if clear benefits were identified, there are significant concerns about the potential harms arising from such screening now. 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 [13, 14].

Mild Cognitive Impairment (MCI) is a construct which represents detection at T2 [3] when the earliest clinical signs of dementia may be emerging. Whilst MCI as a construct has been increasingly used in the past decade across both research and clinic settings, there have not, until recently been any established consensus guidelines for diagnosing MCI [15], [16]. Evidence indicates methods to diagnose MCI require further development [16, 17, 18], especially as not all those with MCI will go on to develop dementia [19]. Limited evidence exists concerning the factors which are predictive of this transition [15].

A number of studies identify that individuals feel very uncertain after being given a diagnosis of MCI, that they do not always receive appropriate support following a diagnosis and that they feel that they have nowhere then to turn [20, 21]. While concerns continue to exist around the utility of the category of MCI, and its application in clinical practice, revisions to the

2013 DSM- V major diagnostic classifications propose a category which will replace the label of MCI with Minor Neurocognitive Disorder [22]. This is an area that is in a state of change and there is a need for all involved in policy development and clinical practice to be actively aware of changes as new evidence emerges.

- **Dementia Diagnosis at T3 and T4**

- Many people currently do not receive a diagnosis at all, and if they do, it is at a later point in their experience of dementia [3]. Many factors are thought to influence this delay including:
 - The significant stigma associated with dementia held by the general public and professionals;
 - The availability and accessibility of diagnostic services;
 - The availability of interventions and support following diagnosis.

These factors have a profound impact both on the number of people seeking help and the point at which help is sought. Thus Prince et al. [3] identify that currently it is more appropriate to bring forward the point of diagnosis to the earliest stage possible – T3.

There are a number of compelling reasons for supporting people to come forwards for investigation of cognitive changes:

- There are many treatable reasons why people experience confusion. The investigations completed as part of the diagnostic process will ensure these are identified and dealt with promptly;
- There are some benefits from pharmacological treatments for some individuals following diagnosis. These do not provide a cure, but may help with symptom control;
- New treatments are likely to have more benefit in these early stages.

National strategies agree that one of the main reasons for providing people with an early diagnosis is to provide the foundations for living well with dementia, including having information, opportunity to adapt and maintain valued life experiences and making plans for the future [23]. 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 [24, 25, 26]. There are significant challenges facing the person and their family in undergoing assessment: 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 [25].

Thus early and timely diagnosis requires:

- A sensitive and staged approach to assessment – which begins by a societal response to challenging the stigma associated with dementia through public and professional education, which informs and educates people about the advantages of seeking a diagnosis;
- Assessment of difficulties, a comprehensive assessment, and a sensitive process of diagnostic disclosure;
- Early intervention and care planning for the future [25, 3, 26, 27].

ALCOVE QUESTIONNAIRE SURVEY

Questionnaires were completed by a variety of sources – the majority being returned by lead clinicians. Analysis of responses from the 24 countries has highlighted a range of similarities and differences in terms of self-reported current practices across the EU.

- **Most countries report missing 40-60% of theoretical dementia diagnoses:** Some countries reported missing above 60% and some reported missing only 30%. When a diagnosis is made it tends to be when the dementia is already at a moderate or late stage. An ageing population is a common issue across the EU with around 10-20% of the population within each country being 65+ (6-10% are 75+ and 1.5-3% are 85+).
- **Overall, four main professions were identified as being responsible for the majority of the key tasks involved in the diagnosis of dementia:** These were General Practitioners, Neurologists, Geriatricians, Psychiatrists. Other professionals were involved in assessment, case management, follow-up and monitoring including Nursing, Psychologists, Neuro-psychologists and Occupational Therapists.

The prevalence of the different professionals is country specific and varies widely. The EU median of the different key professionals per 1,000 citizens aged 65+ is GP's = 3.47 GPs; Psychiatrists = 0.61; Neurologists = 0.35; Geriatricians = 0.09 and Old Age Psychiatrists = 0.02. The more specialist professions in the diagnosis of dementia are less widespread. Typically, GPs make the diagnosis in the majority of simple cases whereas it is specialists who are involved in the diagnosis of complex dementias. The average waiting time from referral to see a specialist for assessment was reported as eight weeks or less by 81% of countries responding, with nearly a third of countries reporting four weeks or less.

- **Most EU countries report having screening services for dementia and MCI:** These appear to be mainly undertaken by hospital based staff. However, it is unclear whether this term is used consistently across the EU. It may be that this is case detection for “at risk” groups (such as hospital patients over the age of 75) rather than population screening per se.

The vast majority of countries report the presence of memory clinics although geographical and population coverage is not considered to be widespread. There is also variation between countries in terms of memory clinic coverage, with the EU median being approximately 50% coverage by memory clinics. Around 50-60% of countries felt they had good coverage by dementia specialists and specialist memory centres. Overall, the opinion in most countries is that memory assessment is accessible to all people but a sizeable proportion (41%) reported that it was not.

Magnetic Resonance Imaging scans were generally the most commonly used type of medical imaging, except for people in late stage dementia, when Computed Tomography scans were more common. For late stage dementia imaging was much less commonly used. The actual imaging used across all people with dementia was reported as being generally similar to that proposed by the official guidelines, although in some cases availability of equipment or resources meant that it was not always possible to follow the guidelines. Cerebrospinal fluid biomarkers were not routinely measured in any country, and where they were measured it was generally for specific patients or for research.

In terms of assessing cognitive function the Mini-Mental State Examination and Clock Drawing Test were by far the most commonly reported.

- **The information on post diagnostic support and interventions was sparse:** Only 61% of those countries responded saying that they always or often provided information about dementia and only 39% reporting that they provided education and social support. More specifically, therapeutic interventions such as cognitive stimulation therapy were much less frequently reported.
- **Legislation in general for people with dementia was varied:** Approximately one-third of respondents reported that they did 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 was reported that it was often not consistently implemented, supported or promoted. For example, many questionnaire respondents reported that greater 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 (on this topic see also p. 78).
- **Almost all countries report having dementia awareness campaigns for both professionals and the general public:** Only 43% of countries reported having specific policies in place to improve the quality of diagnosis. In the countries that had policies they tended to report diagnosis being made at an earlier stage. Only four countries responded by saying they had integrated dementia pathways. Without these elements it is difficult for people with symptoms and professionals to understand clearly the process of diagnosis. Developing such information would therefore be important to help different groups and services fit together and potentially improve the timeliness of dementia diagnoses.
- **The guidelines and policies would help to support GPs in their role,** especially as it is reported by 70% of the countries that GPs have inadequate training in diagnosing dementia and in recognising 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.

If it is recommended that people are diagnosed at an earlier stage, the complexity of the diagnostic process increases. In terms of workforce planning therefore the non specialists either need ways of dealing with this complexity or more specialists will be required.

RECOMMENDATIONS FOR DEMENTIA DIAGNOSIS

Taken together, the recommendations from the literature and the current reported situation across the European Union 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 are available to bring benefit to the person and his or her 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:

- . The provision of pre-assessment counselling which should address:
 - Provision of information concerning the diagnostic assessment process;
 - Possible outcomes of the assessment process;
 - Promoting rights to choice and control over whether to go forward for diagnosis.
- . Where and who should be present for diagnostic feedback;
- . What interventions can be offered following diagnosis;
- . A sensitively delivered process of disclosure of the diagnosis;
- . 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:

- . Initial detection of cognitive difficulties and other symptoms indicative of dementia;
- . Assessment to decide whether symptoms are due to dementia or not;
- . If dementia is present, to achieve diagnosis of the cause and relevant co-morbidities;
- . 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 [28, 29, 30, 31, 32, 33, 34].

Systems need to be in place so that professionals stay up to date with the clinical criteria for diagnosis.

Biomarkers (Cerebrospinal Fluid 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 an 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 MCI) 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 categories 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 dementia detection role.

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.

STRATEGIES FOR HEALTH POLICY FOR DEMENTIA DIAGNOSIS

The recommendations relate to the key areas identified by the work and are presented as strategies for health policy in the form of pyramids. These pyramid diagrams could be utilised at a national or local level to benchmark and plan service provision.

STRATEGY FOR TIMELY DETECTION

- ALCOVE pyramid for timely detection (Figure 2)

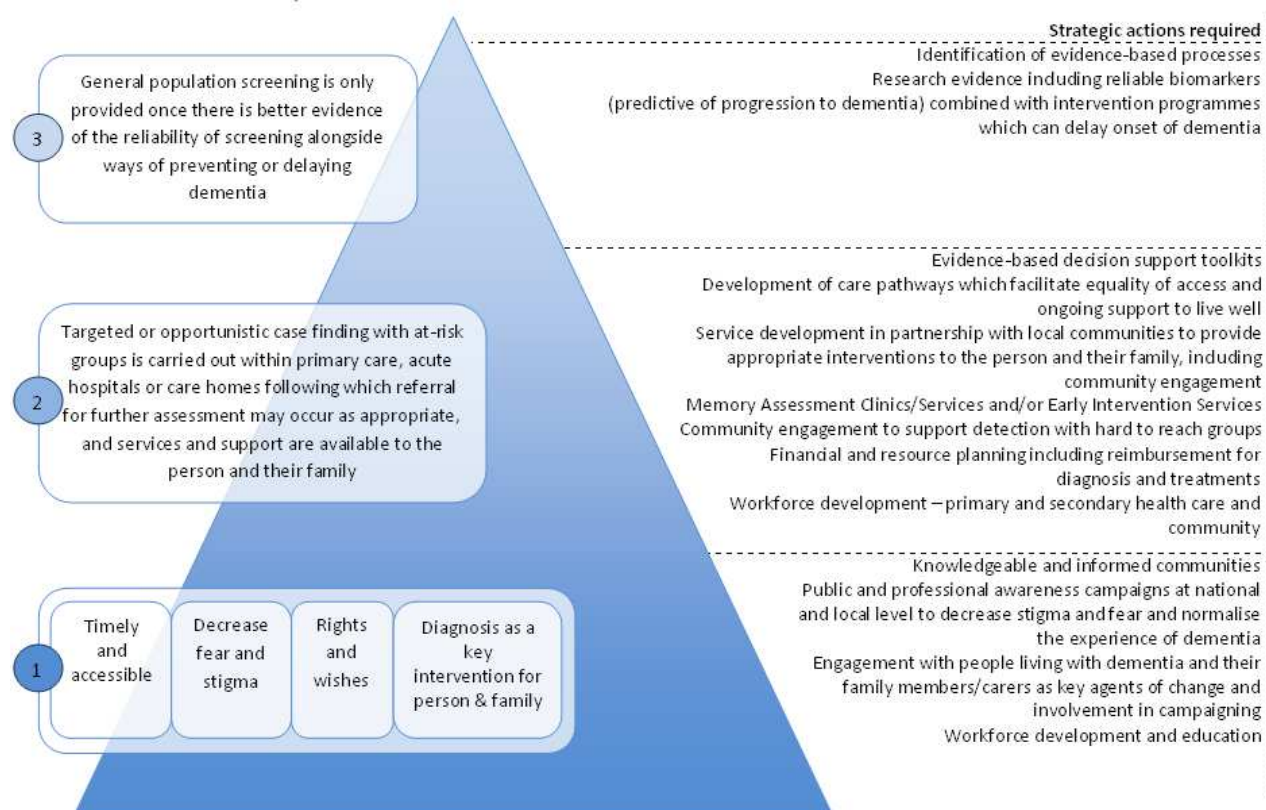


Figure 2. ALCOVE pyramid for timely detection. The principles from recommendation 1 are placed at the base of each pyramid. These are fundamental cornerstones to all issues relating to early diagnosis and represent a baseline standard of care, with subsequent levels covering more sophisticated objectives. The text accompanying the pyramids details the minimum strategic actions that are required at each level to achieve the desired standard of care.

- Questionnaire findings relating to timely detection:** Most countries 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 have opportunistic screening in place in hospital settings.

It is not clear whether different countries use the term 'screening services' to mean the same thing. 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 consistency in the development of services that, integrated with the wider dementia pathway – including workforce training, interventions and support – take into account the broader impact of an earlier diagnosis.

Examples from England and France:

Professionals recognise that family doctors have difficulty in identifying early signs of dementia. Actions are underway in **England** to address these challenges and support family doctors and their colleagues in earlier and timely detection. The Prime Minister's Challenge also addresses timely detection in its efforts to increase the diagnosis rate in England. To bring both the professional and public sides together, initiatives such as the NHS Health Check aim to raise awareness of dementia and the memory services available. Supporting this are national public awareness campaigns which focused on raising awareness of the early signs of dementia, and encouraging people to have potentially difficult conversations with family members who they suspect may have early signs of dementia.

STRATEGY FOR PROCESS OF DIAGNOSIS

- ALCOVE pyramid for process of diagnosis (Figure 3)

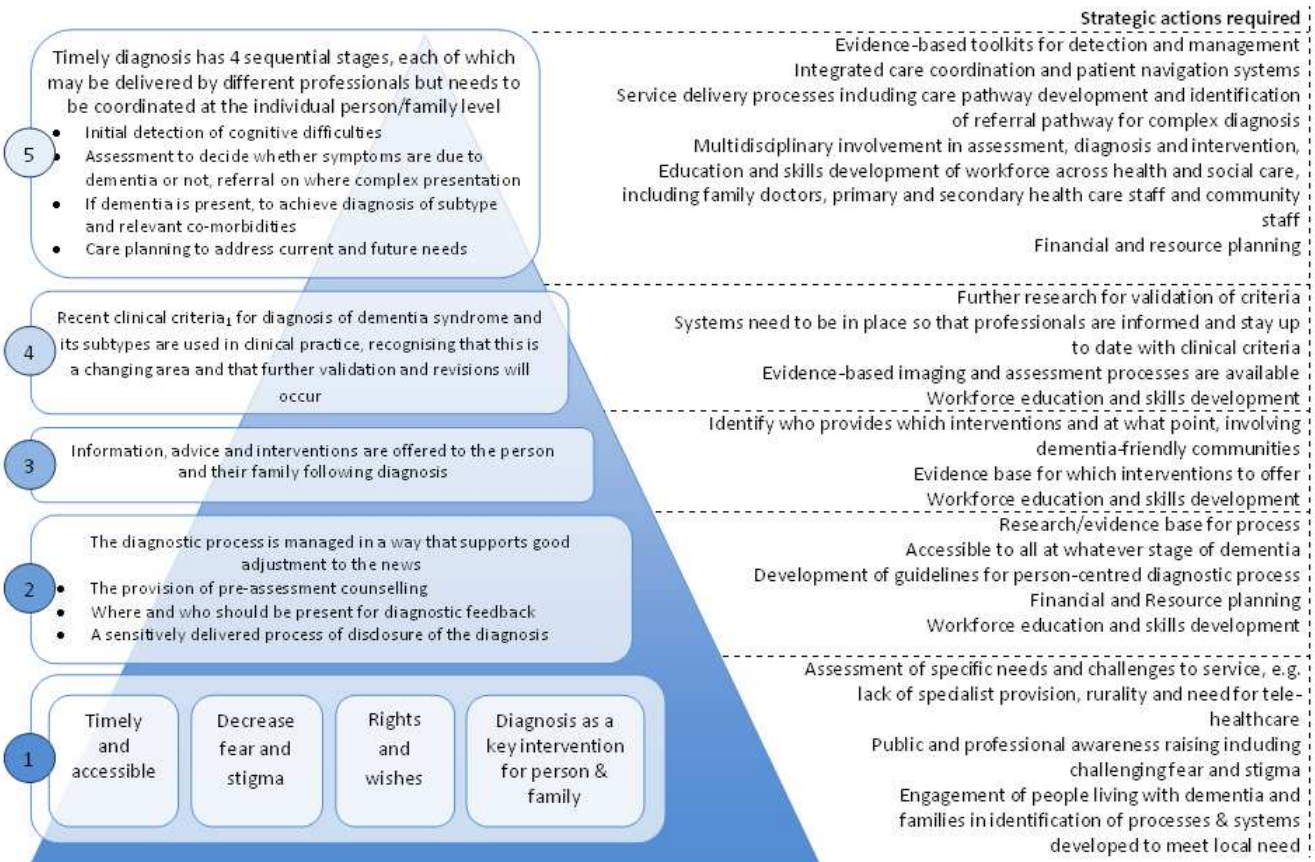


Figure 3. ALCOVE pyramid for process of diagnosis [28-34]. The principles from recommendation 1 are placed at the base of each pyramid. These are fundamental cornerstones to all issues relating to early diagnosis and represent a baseline standard of care, with subsequent levels covering more sophisticated objectives. The text accompanying the pyramids details the minimum strategic actions that are required at each level to achieve the desired standard of care.

- Questionnaire findings relating to process of diagnosis:** Across the EU, most countries have raised 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.

Examples from England and France:

- In England, the Prime Minister's Challenge has encouraged the development of dementia friendly communities, where there is increased awareness, understanding and support for people living with dementia and their carers. The wide reach of these communities include dementia friends, businesses, schools and public sector services such as the fire brigade. In England there has been an increase in the provision of memory services, with 98% of respondents to a national audit saying that they commission memory services or intend to in the future. The quality of memory services is also being addressed through a national programme of accreditation. Local memory services are being encouraged to sign up to this process. To help people with dementia following diagnosis, services such as the Dementia Advisors have been piloted in a number of areas, with some continuing beyond their initial pilot phase. Although an evaluation of these services has yet to report, local evaluations indicate that such services are beneficial for people with dementia and their carers.
- France has seen similar progress in relation to improving the process of diagnosis. The French National Health Authority has helped by publishing good practice information on giving the diagnosis, providing counselling, and defining the role of each person involved in the process. The process itself has two stages, initially giving the diagnosis, followed by confirming and explaining the diagnosis and providing support. This process is supported by the creation of home visits carried out by family doctors, which allow the person with dementia and their family to be part of decisions around their therapeutic, medical and social care needs. France has also increased the number of memory units, especially in areas not covered previously, and created a national network of such units. These units offer specialised medical consultations and have minimum staffing requirements. In addition to these units, they have also created a number of specialist memory resource and research centres which provide a range of services including research, specialist consultation and education and diagnosis in the most complex cases.

STRATEGY FOR COMPLEX DIAGNOSIS

- ALCOVE pyramid for complex diagnosis (Figure 4)

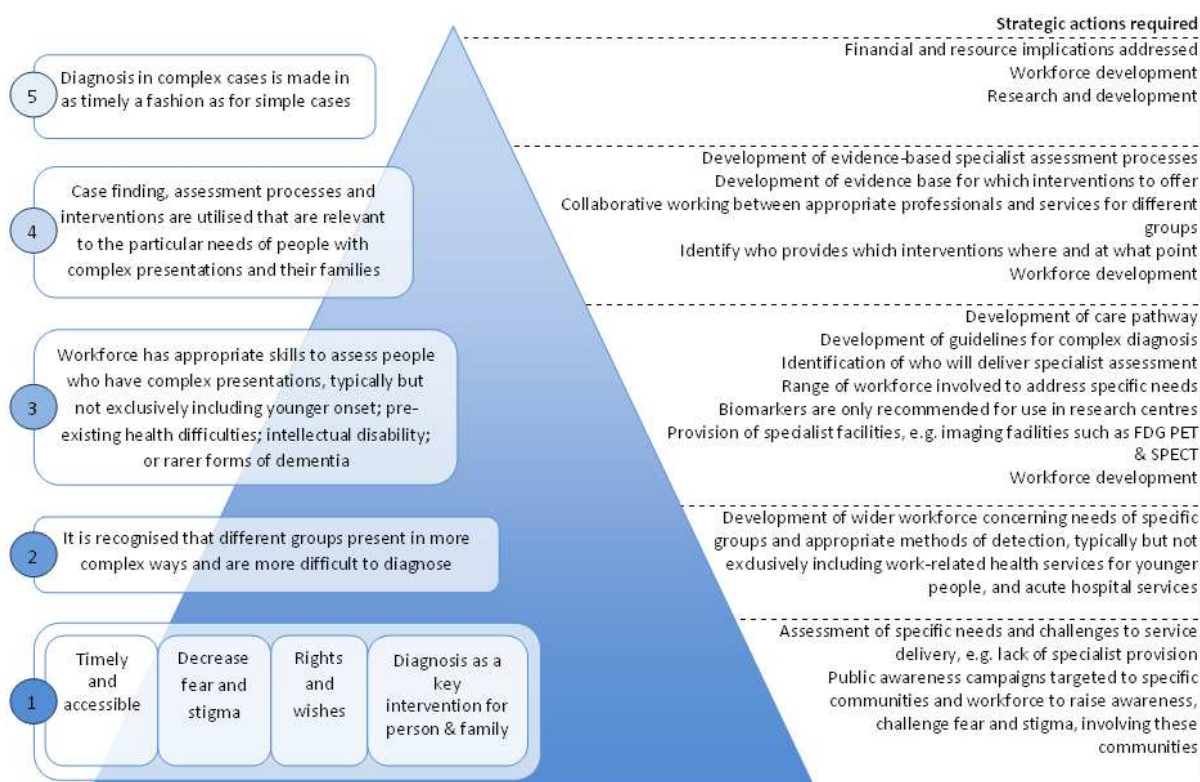


Figure 4. ALCOVE pyramid for complex diagnosis. The principles from recommendation 1 are placed at the base of each pyramid. These are fundamental cornerstones to all issues relating to early diagnosis and represent a baseline standard of care, with subsequent levels covering more sophisticated objectives. The text accompanying the pyramids details the minimum strategic actions that are required at each level to achieve the desired standard of care.

- Questionnaire findings relating to complex diagnosis:** 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.

Examples from England and France:

- In England, there is recognition that there is a need in relation to the availability and provision of information for specific groups whose diagnosis may be particularly difficult or who may not easily access services. This is being addressed by an equalities action plan and covers people who have co-existing disabilities or health difficulties, people from migrant communities and younger people with dementia.
- France has also made progress with complex diagnosis through increasing the number, and consequently coverage, of CMRR (Centres Mémoire de Ressources et de Recherche). These specialist centres provide diagnosis in the most complex cases and for the earliest forms of dementia. In addition, help for younger people with dementia has been provided by establishing a reference centre to develop research and evidence for medical and psycho-social care and standards of practice with younger people with dementia.

STRATEGY FOR PEOPLE REPORTING EARLY COGNITIVE CHANGES (CURRENTLY MILD COGNITIVE IMPAIRMENT MCI)

- ALCOVE pyramid for people reporting early cognitive changes (Figure 5)

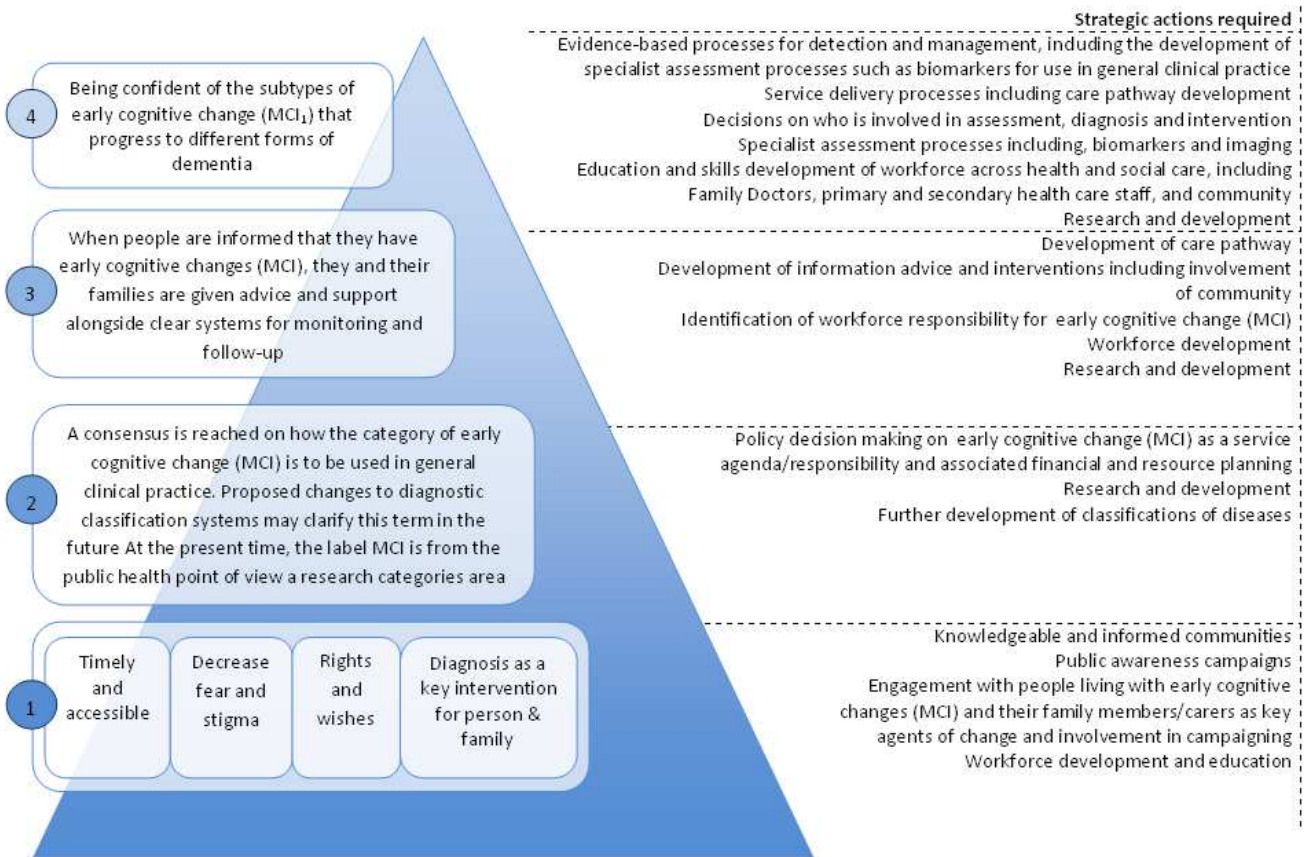


Figure 5. ALCOVE pyramid for people reporting early cognitive changes. The principles from recommendation 1 are placed at the base of each pyramid. These are fundamental cornerstones to all issues relating to early diagnosis and represent a baseline standard of care, with subsequent levels covering more sophisticated objectives. The text accompanying the pyramids details the minimum strategic actions that are required at each level to achieve the desired standard of care.

- Questionnaire findings relating to early cognitive changes:** 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 focusing 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.

STRATEGY FOR WORKFORCE

- ALCOVE pyramid for Workforce (Figure 6)

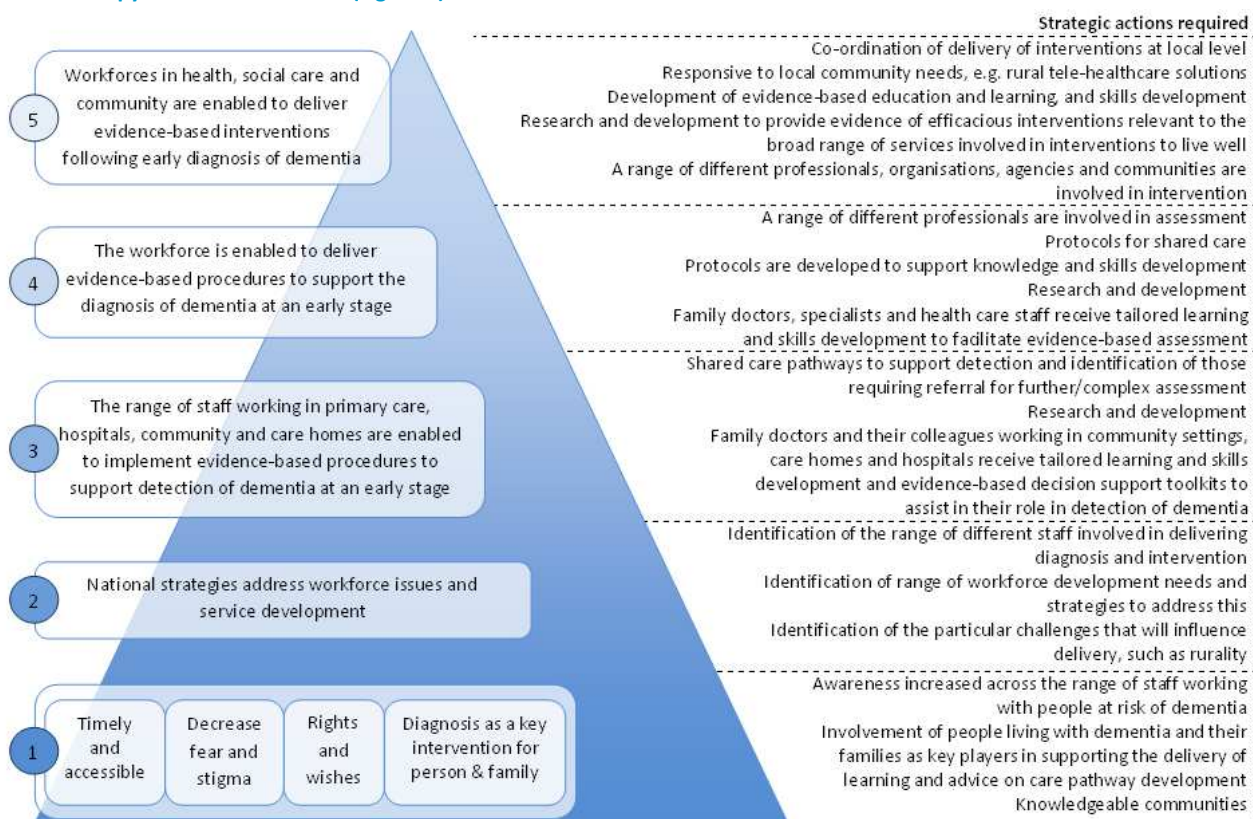


Figure 6. ALCOVE pyramid for Workforce. The principles from recommendation 1 are placed at the base of each pyramid. These are fundamental cornerstones to all issues relating to early diagnosis and represent a baseline standard of care, with subsequent levels covering more sophisticated objectives. The text accompanying the pyramids details the minimum strategic actions that are required at each level to achieve the desired standard of care.

- Questionnaire findings relating to workforce:** 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 that was highlighted as needing improvement in every country was 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.

Examples from England and France:

- In England, the recognition that the range of professionals who come into contact with people with dementia need better education and training has resulted in a number of on-going initiatives to embed dementia skills and knowledge and competencies within the workforce, including medical and nurse education, core common principles in practice, an e-learning package for health and social care staff, and a website for sharing good practice.
- Improving the workforce has also been an aim in France, and has focussed on clarity of individual staff roles within. For example, the professional team in all memory units will include a doctor and is highly likely to have a geriatrician and either a psychologist or a neurophysiologist. The French National Health Authority has published good practice information on giving the diagnosis, providing counselling, and defining the role of each person involved in the process. This helps professionals to have a clearer understanding of where they fit in the wider care pathway. In addition, guidelines for practitioners have been updated according to clinical guidelines on diagnosis and describe ideal clinical pathways.

CONCLUSIONS

Achieving a timely diagnosis of dementia is something that is supported by the research literature. It is something that many European countries see as important and an area that they would like to improve upon. Timely diagnosis needs to be based within a context that decreases fear and stigma about dementia; respects the centrality of the rights and wishes of the person with suspected dementia; recognises that the diagnosis of dementia is a key intervention and that the needs of the person and their family/significant others are central to assessment, diagnosis and post-diagnostic interventions. Using the recommendations set out in this chapter it is possible to benchmark the progress at a local, national and European level in the key areas of timely detection, the diagnostic process, complex diagnoses, response to early cognitive changes and work-force. This is an area where new evidence is emerging and it is important that clinicians, policy makers and citizens have up-to-date information in order to make informed decisions.

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