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Clinician Survey: Dementia Diagnostic Processes and Practices in Ireland

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1. Introduction

In Ireland, current estimates on the prevalence of dementia suggests that there are over 55,000 people living with dementia in the country and projections propose that this may rise to 94,000 by 2031 and 152,000 people by 2046¹.

Dementia is commonly used as an umbrella term to refer to a range of progressive conditions affecting the brain² that result in structural and/or chemical changes, with shrinkage in the volume of the brain and damage or death of neurons³. It is characterized by a decline in one or more cognitive domains (learning and memory, language, executive function, complex attention, perceptual-motor, social cognition), interfering with daily function and independence⁴.

Over recent years there has been a welcome change in reframing the focus of dementia care on the retained abilities and capabilities of people with dementia rather than on lost abilities⁵. Timely diagnosis provides people with dementia time to plan for the future, potentially slow down the progression of the condition and also play a more active role in the design and provision of services through participation and feedback^{3,6}.

In recognition of this, The Irish National Dementia Strategy (2014) identified timely diagnosis and intervention as one of the six priority areas within the strategy. Two actions within the strategy directly outline the role of the Health Service Executive (HSE) in developing dementia diagnostic services in Ireland:

“The Health Service Executive will develop a National and Local Dementia Care Pathway to describe and clearly signpost the optimal journey through the system from initial presentation with worrying symptoms, through to diagnosis, including levels of intervention appropriate to need at any given time.”

“The Health Service Executive will review existing service arrangements so as to maximise the access that GPs and acute hospital clinicians have to specialist assessment and diagnosis of dementia, including Old Age Psychiatry, intellectual disability services, geriatric medicine, neurology services and memory clinics.”

In order to address these actions, the National Dementia Office (NDO) established the Dementia Diagnostic Project in October 2017, supported by a multidisciplinary steering group with representation from Gerontology, Psychiatry of Later Life, Neurology, Allied Healthcare Professionals, Psychology, a person living with dementia and a family carer.

In order to ensure the work of the Steering Group is informed by national and international best practice, a literature review was commissioned and completed by UCC5. The NDO carried out a review of memory clinics, in conjunction with DSIDC⁷, and met with the Irish Dementia Working Group and the Dementia Carers Campaign Network to carry out a needs analysis based on lived experience.

In order to further inform the work of the group, this review of diagnostic practices and processes was conducted between November 2018 and January 2019.

2. Methodology

The target audience for the survey were Clinicians most likely to be involved in the assessment and diagnosis of dementia. The names of 185 clinicians, including Geriatricians (n=100), Neurologists (n=41) and Psychiatrists of Later Life (n=44) were identified through HSE contacts and other resources. Both public and private clinicians were included. E-mail addresses were available for 86% of this cohort (n=159).

A questionnaire was developed and feedback obtained from members of the Diagnostic Project Steering Group. In November 2018, 86 Geriatricians, 39 Neurologists and 34 Psychiatrists of Later Life (N=159) in Ireland were e-mailed the questionnaire on dementia diagnosis processes and practices in Ireland. The questionnaire (Appendix 1) was available via a survey monkey link, and was available to be e-mailed as a word document on request. A reminder e-mail was sent in December 2018, and a third follow-up reminder (individually addressed) was sent in January 2019.

3. Respondent Profile

A total of 56 clinician responses were received, giving an overall response rate of 35%.

Geriatricians were the largest group of responders, though they had the lowest discipline specific response rate (n=24, response rate 28%), followed by Neurologists (n=19, response rate 49%) and Psychiatry of Later Life (n=13, response rate of 38%).

Just under half of responses were received from Dublin. Figure 1 illustrates the geographic spread of responders.

County	Responses
Dublin	29
Louth	1
Meath	1
Kildare	1
Kilkenny	4
Tipperary	1
Waterford	2
Cork	8
Kerry	1
Galway	3
Mayo	2
Roscommon	2
Laois	1
Total	56

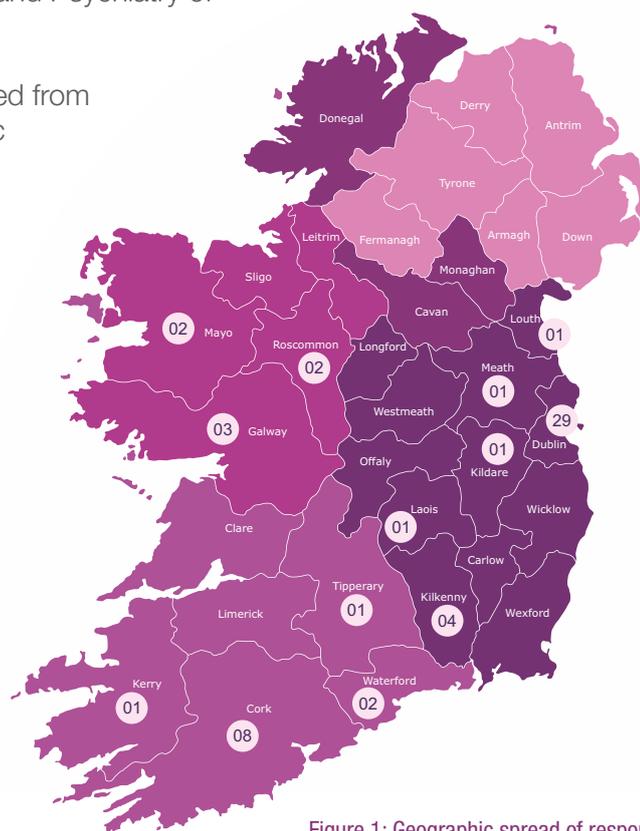


Figure 1: Geographic spread of respondents

The majority of respondents (96%, n=54) assess people for suspected dementia, while 2 respondents (4%) do not.

Of the two who responded that they do not assess people for dementia, both were Geriatricians. Both respondents confirmed that they receive referrals for assessment of suspected cognitive impairment and identify people with suspected cognitive impairment in their routine clinics. When asked where they refer people for assessment and diagnosis, one respondent identified the memory clinic in St James Hospital, while the other responded that they would see the person themselves. Both were from Dublin and both reported that they felt there were adequate diagnostic services in their area.

4. Referrals

The 54 clinicians who do assess people for suspected cognitive impairment were asked to estimate how many people they would assess per week, month or year. There was a broad range of responses to this question, with clinicians reporting that they assess between 1 and 100 people per month, but the majority (74%) saw 1-20 people per month, with a median of 12. The table below illustrates the categorisation of responses.

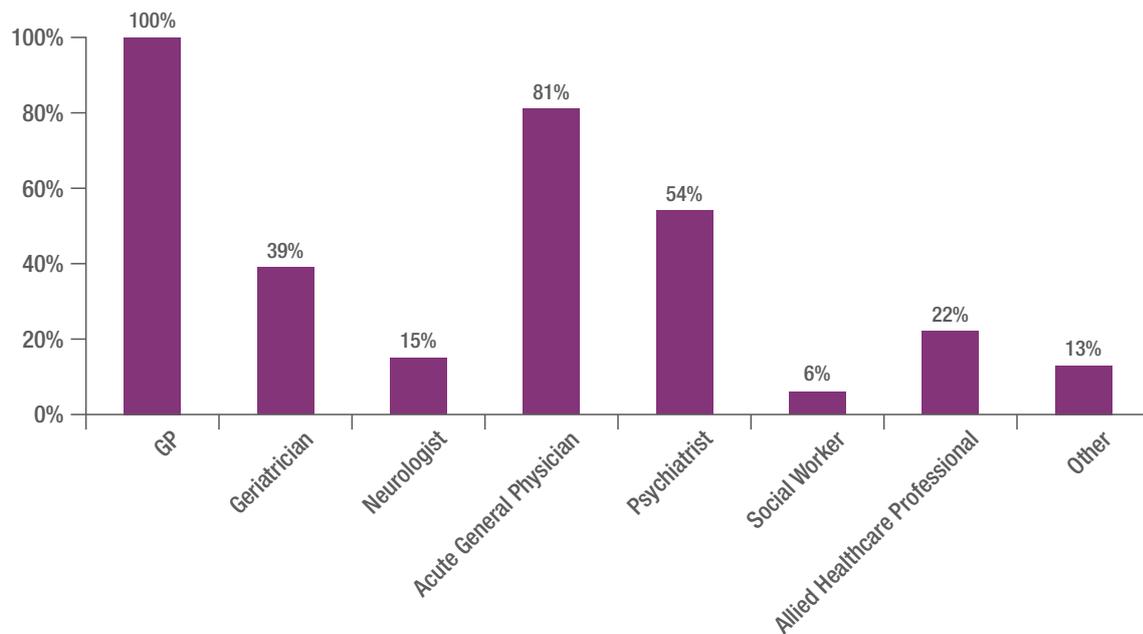
Table A: Numbers Assessed per Month

Categories of Number of People Assessed Per Month								
	1-10 people per month	11-20 people per month	21-30 people per month	31-40 people per month	48 people per month	80 people per month	100 people per month	TOTAL people per month
No. of Clinicians	24	15	4	7	1	1	1	53

One Neurologist reported assessing approximately 6 people per year.

All respondents identified that GPs refer to them, with a mixture of other professionals identified as referral sources, as illustrated in Figure 2.

Figure 2: Referral Sources

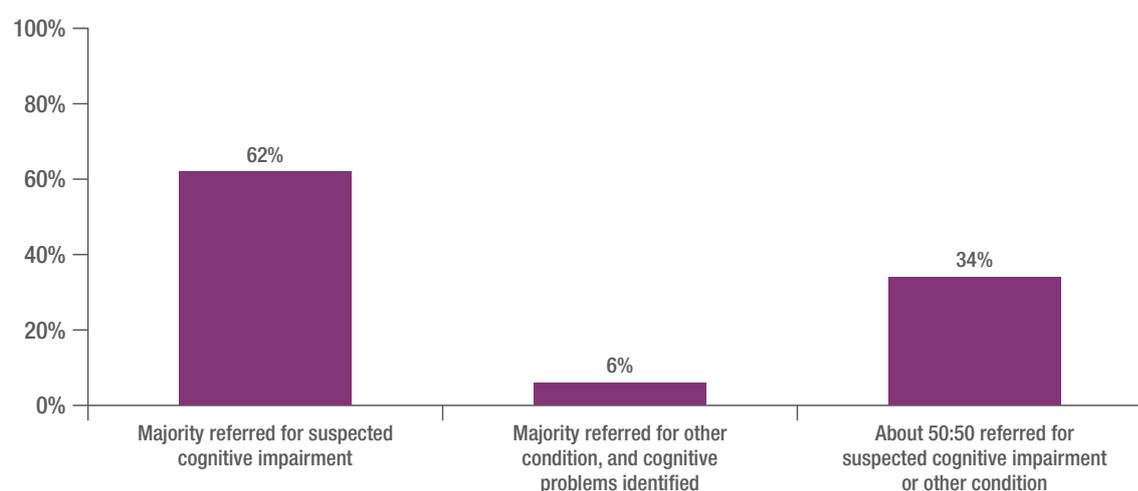


The data indicates good cross-referral between clinician groups, with less strong referral links with allied healthcare professionals. Social workers were the least common source of referral. Within the 'Other' category a number of referral sources were identified by individual respondents:

- direct referrals from OTs
- solicitors
- PHN via GP
- Surgical Teams
- From Rapid Access Clinic at another hospital (independent)
- Other hospital sub-specialists/consultant colleagues.

Clinicians were asked whether suspected cognitive impairment was the primary reason for referral or whether it had been identified in the course of managing another condition. Three response options were given, as illustrated in Figure 3 below:

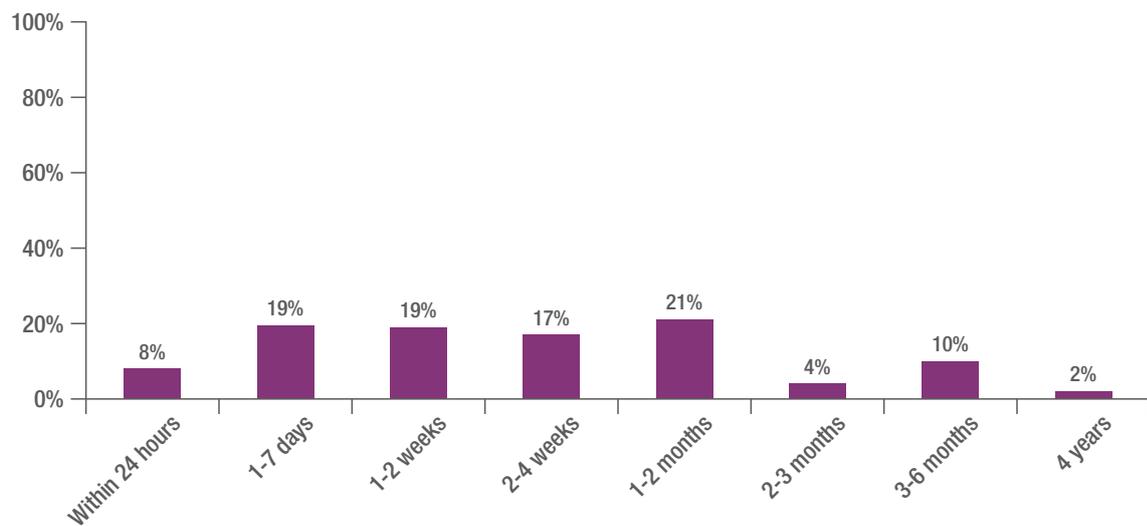
Figure 3: Reason for Referral



5. Waiting Times

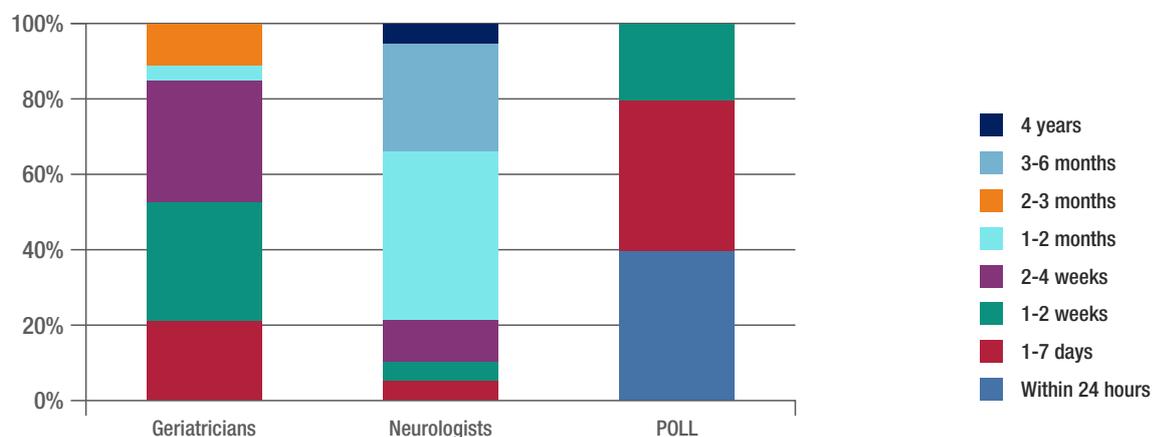
Respondents were asked to estimate average waiting times for both urgent and new referrals. Responses for urgent referrals ranged from less than 24 hours to 3 months, with one respondent identifying a 4 year waiting list for all referrals as illustrated in Figure 4.

Figure 4: Waiting Times for Urgent Referrals



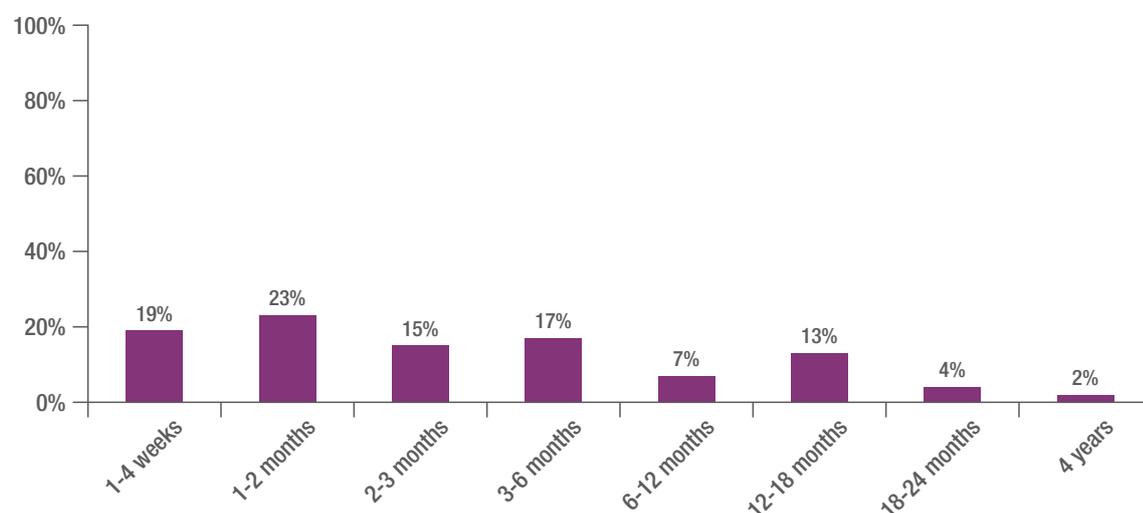
A breakdown of waiting times for urgent referrals by clinician group is illustrated in Figure 5 below. There is a good deal of variation in waiting times between the groups, with Neurology having the longest waiting times of the three groups, while POLL have the shortest waiting times.

Figure 5: Waiting Times for Urgent Referrals by Clinician Group



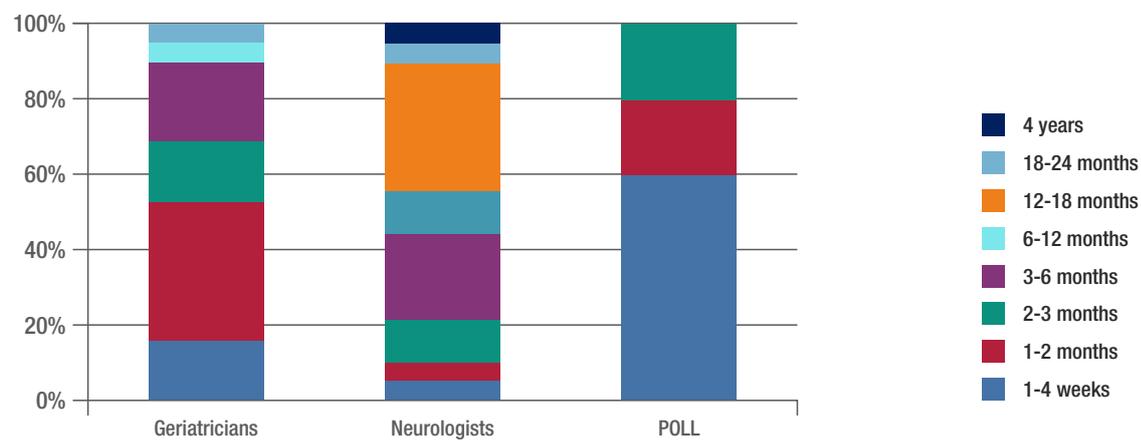
Waiting times for routine referrals ranges from within a week to 2 years, with one clinician identifying a 4 year waiting list for all referrals, illustrated in Figure 6.

Figure 6: Waiting Times for Routine Referrals



Once again waiting times were broken down by clinician group, as illustrated in Figure 7. A similar pattern to urgent referral waiting times is highlighted, with Neurology having longer waiting times, and POLL having substantially shorter waiting times.

Figure 7: Waiting Times for Routine Referrals by Clinician Group

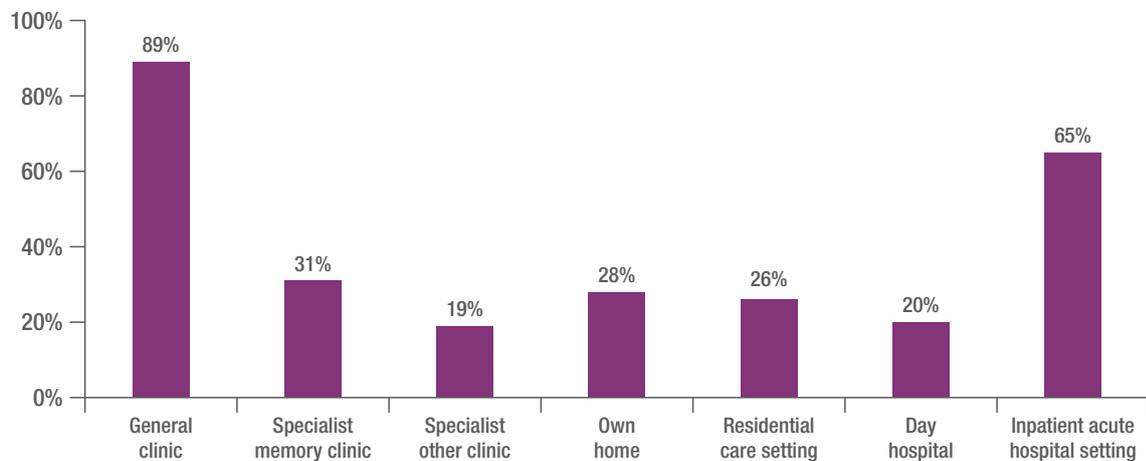


6. Assessment

6.1 Place of Assessment

Clinicians were asked to identify where they carry out assessment for suspected dementia, with the option of ticking more than one response. The majority of clinicians (89%, n=48) responded that they assess people in a general clinic, with assessment in an inpatient acute hospital setting being the second most common place for assessment. 31% of respondents (n=17) assess people in a specialist memory clinic, as illustrated in Figure 8 below:

Figure 8: Location of Assessment



The majority of clinicians (81%, n=43) reported assessing people in multiple locations, with just 11 clinicians (20%) reporting seeing people in just one location; in a specialist memory clinic (n=4) and in a general outpatient clinic (n=7).

A small number of respondents (29%) reported that they visit long-term care units to assess people for suspected dementia. Within specific clinician groups this varied considerably, with 64% of Psychiatry of Later Life clinicians visiting long-term care units, 32% of Geriatricians and 5% of Neurologists.

6.2 Assessment Population

The majority of respondents assess people under 65 years, with a smaller number indicating that they assess people living with an intellectual disability as outlined in Table B below.

Table B: Assessment Populations

	Yes	No
People under 65	85%	15%
People with an ID	56%	44%

Again there was considerable variation between clinician groups, as outlined in Table C below.

Table C: Assessment Population by Clinician Group

Assess People Under 65	Yes	No
Psychiatry of Later Life	64%	36%
Geriatricians	82%	18%
Neurologists	100%	-

Assess People with an ID	Yes	No
Psychiatry of Later Life	18%	82%
Geriatricians	55%	45%
Neurologists	79%	21%

As outlined in the table above, the majority of Psychiatrists of Later Life and Geriatricians do assess people under 65, though these services formally have a remit for people aged 65 years and over. However, comments received indicate that there are barriers and restrictions to delivering this service:

"Only rarely see [people] under 65s - would like to do more of this but not enough resource"

"I see predominantly over 65s, I prefer for those under 65 to see a neurologist or attend St James but will see under 65s and assess need to refer to other service first in some cases"

"Occasionally I will be asked to assess patients aged between 55 and 64 years. I usually offer a diagnostic assessment and one or two follow up reviews but advise patients' GP that my ongoing remit is with patients aged 65 years and over"

While just over half of all clinicians reported that they assess people with an ID for suspected dementia, some comments received from all clinician groups suggested more education, training and support is required in this area:

"ID: Major deficit, I feel unqualified to assess properly and find my intervention unhelpful. Service needs to be properly developed"

"I may be referred patients with ID and I would initially see if a more appropriate assessment could be made by ID physician but if not - I will see them"

6.3 Assessment Tools and Tests

Respondents were asked to identify the cognitive tools they routinely used when assessing a person for dementia. Responses are illustrated in Figure 9.

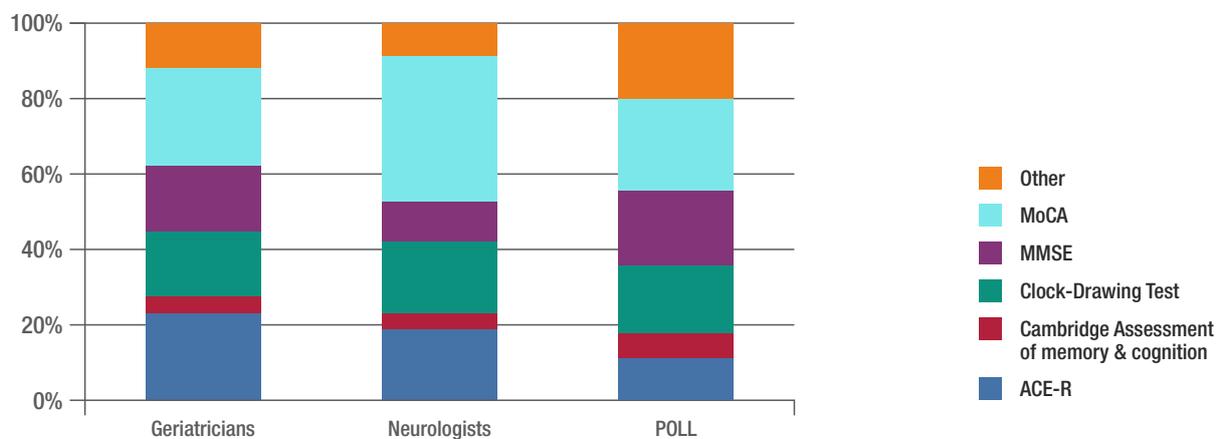
Figure 9: Assessment tools routinely used



The MoCA was the most commonly used cognitive assessment tool, with the ACE-R and the Clock-drawing Test cited as the second most commonly used. Just under half of respondents reported routinely using the MMSE. The least used tests were the 6-Item cognitive Impairment Test, the Alzheimer Disease Assessment Scale and the AMTS.

When the most commonly used assessment tools were compared across clinician groups, it was found that there was some small variation on how often different tools were used by different clinician groups, as illustrated in Figure 10. Psychiatrists of Later Life were the largest group to report using 'other' tools, with RBANS and Restricted Response being the most commonly identified other assessment tools for this group.

Figure 10: Assessment tool usage by clinician group.

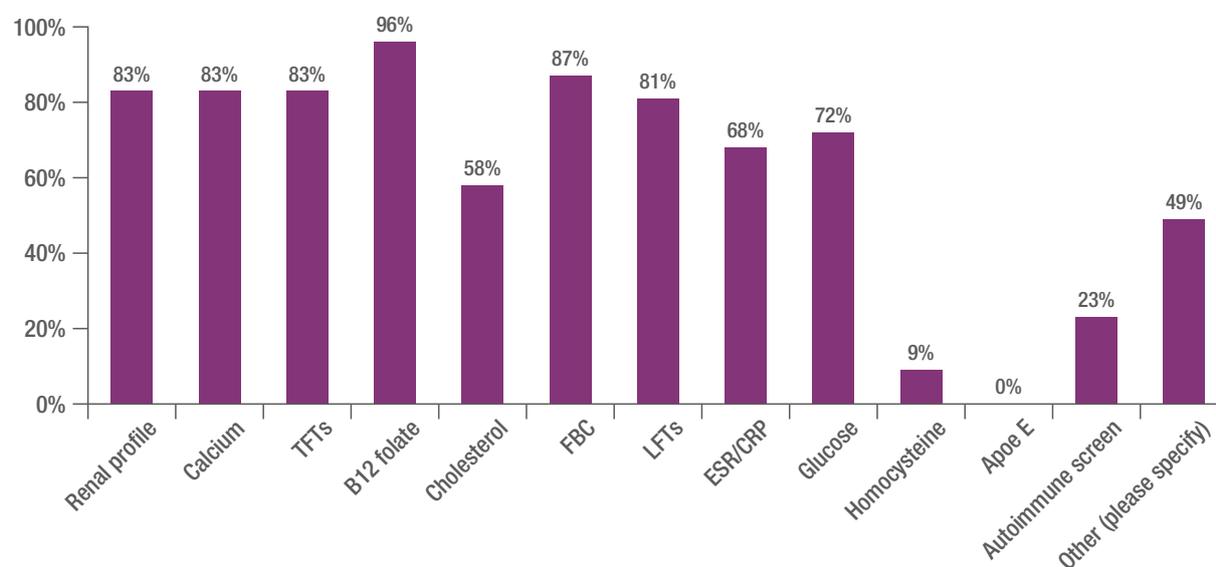


A number of tools were identified in the 'other' category, where both screening and diagnostic tools were identified:

- Wechsler Adult Intelligence Test (WAIS)
- Delayed Word Recall (DWR)
- Frontal Assessment Battery (FAB)
- RUDAs
- Boston naming test
- Frontal Behavioural Inventory
- Informant Questionnaire on Cognition
- Geriatric Depression Rating Scale (GDS)
- Clinical Dementia Rating Scale (CDR)
- The Quick Mild Cognitive Impairment (Qmci) Screen
- ACE III
- Queen Square Cognitive Assessment Book
- RBANs
- Progressive Aphasia Language scale
- Physical Self Maintenance Scale (PSMS)
- Instrumental Activities of Daily Living (IADL)
- Alzheimer's Questionnaire (AQ)

Figure 11 illustrates the blood tests routinely used when assessing a person for dementia.

Figure 11: Blood tests routinely used in assessment for dementia



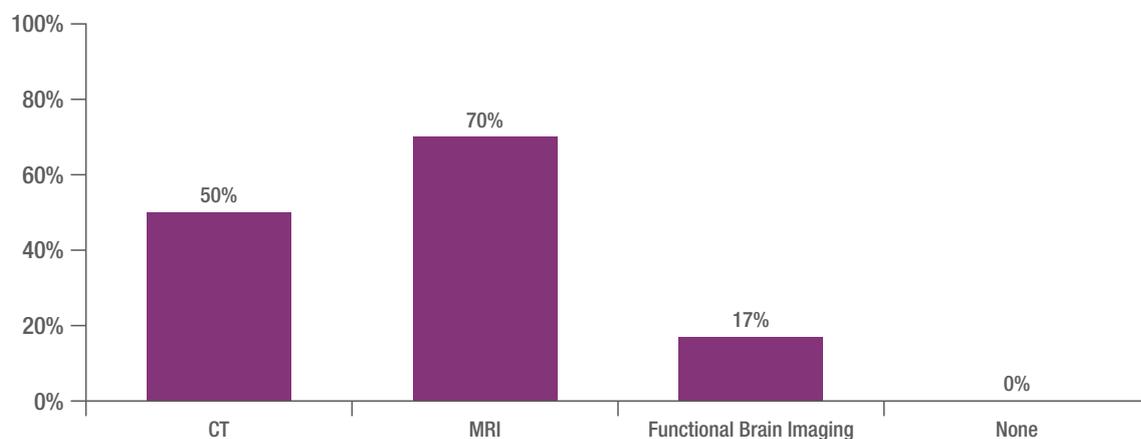
Other blood tests identified as routinely used included:

- HIV
- Vitamin D levels
- ANCA and other autoantibodies
- Iron Profile
- CRP
- Lipid profile
- 25 OH vitamin D
- Ferritin
- ANA (if relatively younger)
- Thyroid function test
- Cholesterol
- Lyme
- PSA
- Syphilis serology
- Triglycerides
- VDRL
- Paraneoplastic antibodies
- Urea and electrolytes
- Liver
- Folic acid
- SP & EP
- Bone profile
- Hba1c
- Paraneoplastic Abs
- Anti-VGKC Ab complex
- Voltage gated potassium channel antibodies (LGI1 & CASPR2)

Two respondents commented that they rely on GP for blood screen, though this is not always fully completed.

Clinicians were also asked to indicate what imaging they routinely used when assessing for suspected dementia, as illustrated in Figure 12.

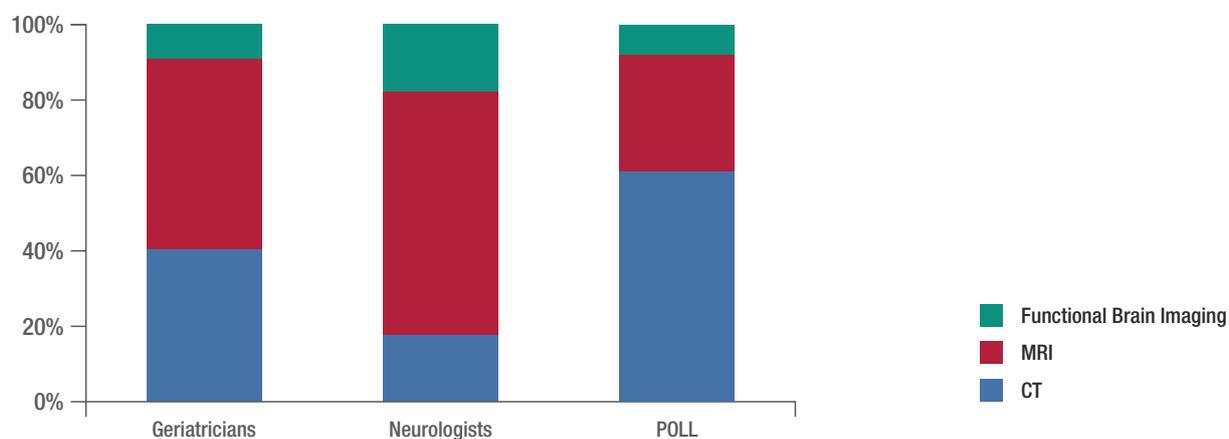
Figure 12: Imaging routinely used when assessing for suspected dementia



MRI was the most commonly used imaging. However some comments received for this question indicate that while MRI is the preferred imaging, barriers remain such a long delays for local public access, and having no local MRI service available. One clinician outlined that they suggest people go privately for MRI and they then review the scans. Some comments identified that imaging would only be routinely used for those under 65 and/or atypical presentations. These caveats suggest that some clinicians may have indicated how often they use imaging in general, rather than how often they routinely use imaging, which may account for the high percentage of imaging use reported.

A breakdown of imaging use by clinician group, illustrated in figure 13, highlights that the majority of neurologists reported that they use MRI, while CT scans are more commonly used amongst POLL. Geriatricians reported using MRI and CT equally.

Figure 13: Imaging routinely used by clinician groups



Respondents were asked if they use CSF analysis to aid diagnosis, and an open ended response option was given. Just under half of clinicians (48%; n=26) reported using CSF analysis to aid diagnosis, while just over half (52%; n=28) reported rarely or never using CSF analysis.

Amongst the group who use CSF analysis to aid diagnosis a good deal of variation was identified in when or how often people use it. The reasons for using CSF analysis included:

- for people under 65
- for rapidly progressive dementia
- for atypical presentations
- where there is a differential diagnosis e.g. white matter disorder or vasculitis.

Overall responses indicate that many clinicians decide whether to use CSF analysis depending on presentation, e.g. one clinician clarified that it would not be used for those with advanced cognitive impairment or with classic history of AD/VD. However, it is unclear from the data collected whether CSF analysis is used to support diagnosis or to rule out other potential conditions.

Amongst the group who do not, or rarely, use CSF analysis, very few reasons were given for this. One respondent outlined that they feel there isn't the capacity to accommodate all those with suspected dementia to have a lumbar puncture performed and many are on anticoagulation which complicates the issue further. Another respondent replied that CSF analysis is a research tool only.

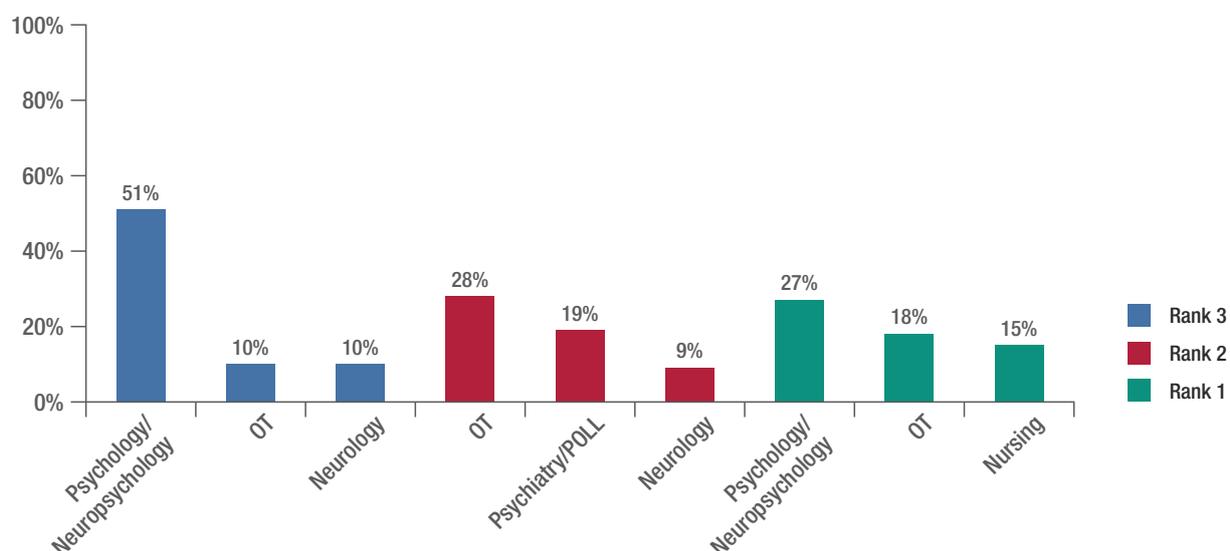
6.4 Collaboration

The majority of clinicians (88%) responded that they routinely collaborate with other disciplines in the assessment of suspected dementia.

The discipline cited as being most routinely involved in collaborative assessments were OTs (61%), other Clinician Specialities (54%), Psychology/Neuropsychology (52%), Nursing (33%), Social Work (13%) and Speech and Language Therapists (13%). Other disciplines less frequently identified included Public Health, Nurse, GP, Pharmacy, Dementia Advisor and a Dementia Community Care Coordinator. Of note is that no clinician identified audiology as a discipline they collaborate with, despite the strong evidence linking hearing loss with dementia assessment.

Respondents were asked to identify what other disciplines they would ideally want to collaborate with, and to rank these in order of preference. Figure 14 below illustrates the top three disciplines identified within each preference category.

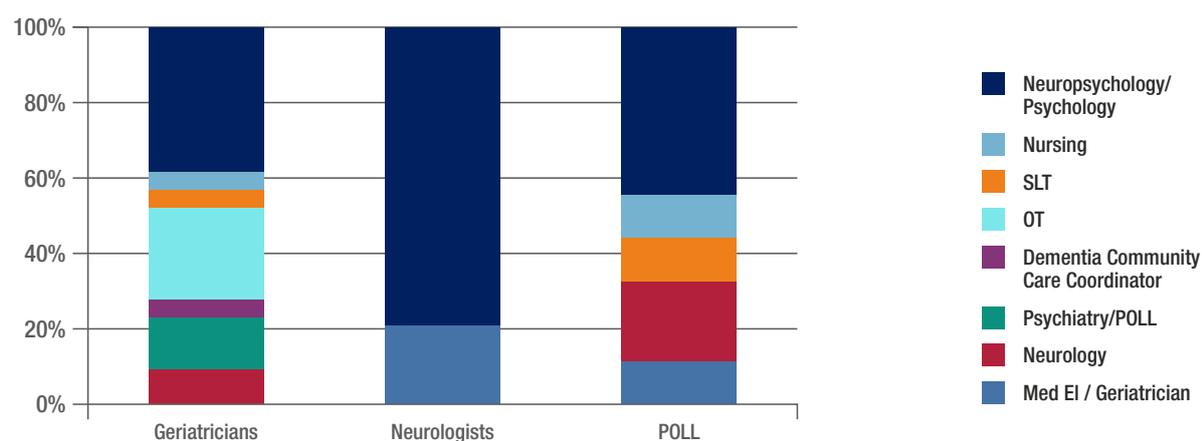
Figure 14: Disciplines ideally wish to collaborate with by preference category



Just over half of respondents identified a psychologist or neuropsychologist as the discipline they would ideally want to collaborate with around the assessment of suspected cognitive impairment/dementia. Some comments indicate that psychology/clinical psychology is needed for more complex cases.

A breakdown of the disciplines ranked as most important by each clinician group is illustrated in Figure 15 below. Geriatricians named a broad range of disciplines they would like to collaborate with, while the majority of neurologists named psychology/neuropsychology as the discipline they would ideally like to collaborate with.

Figure 15: Disciplines ranked number one for ideally collaborating with by clinician group



The identification of Neurology, Gerontology and Psychiatry of Later Life as disciplines Clinicians would like to collaborate with suggests that while there is evidence of good cross-referral between disciplines this needs to be strengthened in some areas.

7. Disclosure and Post-Diagnostic Information and Support

7.1 Disclosure

All respondents identified themselves as the person who would usually disclose the diagnosis of dementia, with three respondents identifying that it would be either themselves or a senior doctor/registrar.

Respondents were also asked to identify who else would be present during disclosure. The presence of a nurse was reported by 45% of respondents, though a small number identified that this would only be 'sometimes'. Over half of these nurses were identified as being ANPs or CNSs (68%), while one person identified the presence of a neurology nurse, and another responded that on occasion the community mental health nurse would be present.

The presence of family members was reported by 29% of respondents, while 14% of respondents identified a social worker as being present (though again, not always). One respondent reported that the ASI Dementia Advisor has been present on occasion while two others reported that trainee doctors or Registrars/SHO may be present.

14% of respondents identified that no-one else is present at disclosure. The reason for this was not recorded, though the comment 'I wish' indicates that it may be due to lack of resources.

7.2 Information given at Disclosure

Clinicians were asked to outline what information is routinely given at the time of diagnosis, with an open-ended response option. The amount and type of information given varied widely, from comprehensive post-diagnostic information;

"General healthy living advice, legal advice, driving and dementia information, accessing community supports information, information on ASI. Information pack is put together depending on the stage of dementia. Patient given typed summary of their assessment and recommendations, also told about living with dementia group and memory strategy group that we run and memory technology room in (locality)"

to information with a more narrow, defined focus:

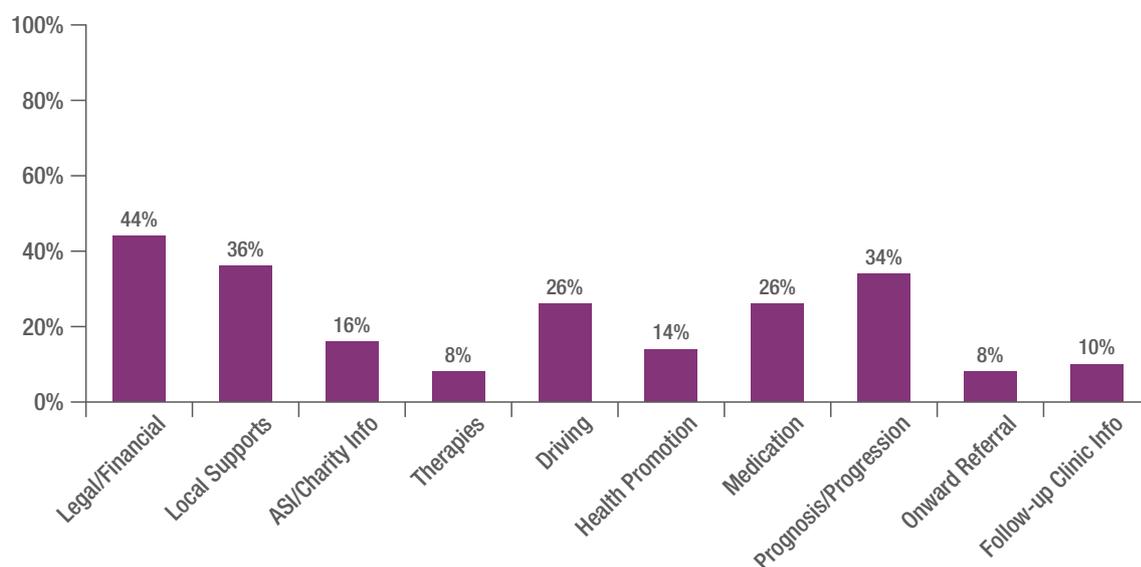
"progression disease, carers burden and management"

"The diagnosis and prognosis that it will get worse but some pills can help to some extent"

Comments received highlighted differing approaches in the disclosure and discussion of the person's diagnosis. Some respondents outlined how they explain the different terms involved (e.g. MCI and dementia) before discussing the diagnosis, while others discuss and explain each of the assessments and what they mean. However, others indicate that they follow different disclosure processes, with one respondent indicating that the full disclosure is given to the family, but a diagnosis of Mild Cognitive Impairment would be given to the patient. Another responded that they would explain that the person has a significant memory problem which is likely to be progressive, but may or may not use a more precise term (e.g. Alzheimer) depending on what the patient appears to want to hear.

Topics most commonly identified in responses are illustrated in figure 16 below:

Figure 16: Information Most Commonly Given at time of Diagnosis



The financial and legal information most commonly given related to Enduring Power of Attorney and Wills. A number of different community based supports were identified and information given on them, though very few responses identified specific therapeutic interventions such as Cognitive Stimulation Groups, Memory Support Groups and Medical Exercise Programmes. A small number of respondents alluded to onward referrals to the PHN or back to the person's GP.

A small number of respondents identified occupational advice, care management and risk management as part of the routine information they provide. 12% of respondents outlined that they provided written information to the person. The type of written information provided varied greatly, with some tailored to the needs of the individual, and others providing information packs that "takes them from diagnosis to death, in theory".

The question of how much information is appropriate to give at the time of diagnosis was discussed by one respondent:

"I usually describe what's normal for ageing, what's mild cognitive impairment and then how they differ from dementia. We then discuss the diagnosis, I outline stage if appropriate, I outline "treatment", I give contact information for the ASI dementia advisor and the local dementia/cognitive impairment support services (excellent resource locally led by OT with specific remit in cognition) and other HSE supports as applicable to this individual. More often than not there is insufficient time or the person has had enough information to take on board at the first encounter for me to broach other topics such as legal matters, care planning etc. These topics are broached at the first follow up appointment. Driving is discussed where there is a likelihood that the person's cognition has deteriorated to a level that would make driving dangerous. Otherwise it is broached at the first follow up"

This response highlights the need for follow up after diagnosis.

7.3 Follow-up after Diagnosis

Respondents were asked to outline what, if any, follow up is there after a diagnosis of dementia is given. An open response option was given for this question. Responses received highlight the wide range of processes regarding follow-up after diagnosis currently followed in clinics nationally.

A small number of respondents outlined post-diagnostic support (PDS) follow up visits, either in the clinic or by telephone. The timing of this follow up varied, with some respondents following up within 4-6 weeks, others within 3 months, while others did not specify a time interval for PDS follow-up. Some

“Clinic visit with cANP, follow up advice/ phone call. All patients/families given contact number for cANP as point of contact and patients followed up in clinic once / twice per year for management of disease progression. Also offer an ‘urgent’ review slot in the Monday Memory review clinic for patient / carer crisis review- we think this has helped avoid > 50 hospital admissions in the last year”

Others responded that follow-up would depend on diagnosis and clinical presentation. Some noted that any new medication or change in medication would instigate a follow up visit. Again the time to follow-up varied. Others responded that all patients would be followed up routinely, either every 6 months or yearly.

“Depending on the person’s needs they are all seen within 6 months, but are seen sooner if there is a more pressing need that needs to be addressed”

The majority of Neurologists who responded identified 3-6 month follow up for younger patients as routine, though one person noted that due to overbooked clinics follow up generally occurs at 12-18 months.

A small number of respondents identified home visits as part of follow-up, with the majority of these within the Psychiatry of Later Life (POLL) services. Some respondents from POLL outlined that people would only be followed up routinely if there was a co-morbid psychiatric disorder.

Overall, clinicians have developed follow-up practices that appear to fit within their own service models and resources available, resulting in a broad range of follow-up processes and practices nationally.

7.4 Discharge from Service

Respondents were asked when they discharge people from their service. A very small number (n=4) responded that they never discharge people, with one respondent indicating this was due to lack of follow-on services. A small number (n=2) indicated that they discharge once diagnosis is confirmed.

The main reasons for discharge included:

- When the person is stable and there are no active issues.
- When the person is stable and has good support.
- When they no longer have Behavioural and Psychological Symptoms of Dementia.
- On entry into Long-Term Care.
- When accessing clinic becomes too burdensome.

A number of respondents highlighted that while they do discharge back to the GP, they will see people again at short notice if a difficulty arises. Once again respondents identified that discharge would be based on clinical need;

“Depends on firmness of diagnosis; involvement of other disciplines; prognosis and clinical course; therapies introduced”

8. Key Components of a Good Service

Respondents were asked to outline what, in their opinion, the key components for a good dementia diagnostic service are. A number of recurring themes emerged from the open ended responses received.

8.1 Rapid Access/Referral Pathways

A number of respondents identified the importance of rapid and early access to assessment for suspected dementia. One respondent identified the importance of good GP networks for education and encouraging early referral.

A smaller number identified the need for clear pathways of care, including referral pathways, pathways to post-diagnostic supports that GPs could also utilise and “agreed pathways of referral between Geriatric Medicine, Old Age Psychiatry and Neurology”.

8.2 Multidisciplinary Team

The importance of having access to a skilled, multidisciplinary team was identified in the majority of responses. A range of disciplines were identified, including nursing/CNS, OT, psychology, neuropsychology, social work, SALT, Psychiatry of Later Life, Neurology and Geriatrics. Some respondents identified the need for staff to have dedicated time, while others outlined the need to have access to good supportive colleagues in other disciplines as needed.

“Adequate number of appropriately trained staff and collaboration with colleagues”

In addition to having skills in assessment and experience caring for people with a cognitive impairment, some respondents identified the need for staff to be empathetic and compassionate.

“Competent clinicians who are empathetic communicators”

“All interactions and care should be person-centred. Compassion is very important”

8.3 Assessment

The majority of respondents identified the need for access to diagnostic tests. This included validated assessment tools, easy access to bloods, imaging, radiology and lumbar punctures/CSF sampling support.

Some respondents also identified the importance of having an appropriate physical space to complete the assessment process, with one clinician highlighting the importance of “a calm, quiet environment”. Having adequate time to carry out assessments was also highlighted as important by a number of clinicians.

“Adequate space and time for patient and family to be seen”

One clinician highlighted the importance of seeing people at home for assessment and diagnosis of dementia.

8.4 Disclosure

The importance of having a good system for diagnosis disclosure and the provision of appropriate information was identified by a number of respondents. This included having an appropriate space for these discussions (as discussed above), and the provision of appropriate verbal and written information on all aspects of care including medical, legal, lifestyle and social care.

“Follow up discussion of diagnosis and other factors that are relevant when giving the diagnosis”

8.5 Post-Diagnostic Support

Having links with adequate post-diagnostic supports and services was highlighted as necessary by a number of respondents. The majority identified that these post-diagnostic supports need to be in the community and therefore links with and information on community services was essential. One respondent identified having links with personnel e.g. Dementia Advisor, was needed to adequately signpost to post-diagnostic services.

“Afterwards good links into the community and voluntary sector that can help with ensuring patients and carers can remain within their communities is vital”

8.6 Continuity of Care

A small number of clinicians identified the importance of continuity of care for the person, highlighting that what should be delivered is an interdisciplinary ‘service’ rather than just a diagnostic clinic. One respondent identified the importance of having a single point of contact within the service, while another outlined the benefit of having a case management model in the latter stages of the condition to support transition from the community to long-term care.

8.7 Other Elements

A number of other elements were identified by single clinicians, including:

- Access to appropriate information at the appropriate stages in the disease.
- Ongoing education for patient and family.
- Having a specialist memory clinic
- *“A normal healthcare system where patients can be seen within a few weeks and followed up within a few months, neither of which we have”*

9. Discussion

This survey identified a good deal of variation in dementia diagnosis processes and practices nationally, mirroring the findings from the NDO/DSIDC (2017) review of memory clinics. While some variation is necessary to ensure that diagnostic services maximise resources available and are flexible enough to adapt to the needs of the individual, the degree of variation identified is indicative of the lack of national guidance for dementia assessment and diagnosis in Ireland to date.

It is unsurprising that GPs were identified as the largest single source of referrals for assessment of suspected dementia as GPs are the first port of call for people concerned about their cognition. The survey also highlighted that the majority of referrals are for suspected cognitive impairment, rather than for other conditions, indicating a good awareness of dementia indicators amongst referrers.

Despite the majority of referrals being specifically for the assessment of suspected cognitive impairment, the majority of assessments are taking place in general clinics, with only 31% of respondents identifying that they assess people in a specialist memory clinic. It is unclear from the results how appropriate the general clinic setting is for assessment, as it is necessary to balance specialist assessment with the need for people with co-morbidities to access care and support at a single point rather than having to attend multiple clinics. However, the fact that 65% of assessments take place in an inpatient acute hospital setting may be cause for concern, as carrying out cognitive assessment to diagnose dementia while a person is acutely ill is not best practice. Further investigation will be necessary to determine what is driving this practice in Ireland.

The variation in tools and tests identified through the survey may be reflective of individual clinician preference, and the clinical presentation of the person being assessed. However the fact that clinicians identified a mixture of screening and diagnostic tools in the 'other' category suggests that the development of a guidance document on appropriate assessment tools for the diagnosis of dementia may be beneficial.

The importance of collaboration was highlighted through the survey, and a core group of Health and Social Care Professionals were identified as having a key role to play in dementia assessment and diagnosis. In identifying disciplines they would ideally like to collaborate with, clinicians highlighted the need for additional resources to ensure that appropriate inter-disciplinary collaboration could occur. In the absence of minimum standards for assessment and diagnosis clinicians often collaborate within available resources, rather than having access to an ideal cohort of disciplines. These results can be used to inform the development of minimum standards, and thus create a framework within which necessary additional resources can be costed and requested.

The greatest level of variation identified was around disclosure practices and post-diagnostic information and support given through the diagnostic services. This reflects the anecdotal feedback from a number of groups, including the Irish Dementia Working Group, the Dementia Carers Campaign Network and the Dementia Diagnostic and Post-diagnostic Steering Groups. Some of the comments received in the free-text option around disclosure indicate that the variation in practice, including the some-time presence of a second HSCP at the disclosure meeting, indicate a lack of dedicated resources, rather than variation in need.

A great deal of variation in the depth and range of information given at the time of disclosure was identified. There appeared to be recognition amongst some clinicians that a great deal of information would be needed by the person following a diagnosis. However in some instances all of this information is conveyed at the disclosure meeting, where the person is unlikely to be in a position to retain the information, or may not yet wish to receive it. Other responses indicate that some clinicians see their role as being purely clinical, and do not provide information beyond prognosis and medication. The survey did not capture the length of time given to disclosure, or where disclosure usually takes place. These results indicate the need for guidance on best practice and additional resources to support clinicians provide the highest quality care at this crucial juncture.

Further discussion is needed to clarify the scope of responsibility of the diagnosing clinician regarding post-diagnostic support and follow-up. Again a great deal of variation is evident, which appears to reflect a myriad of factors, ranging from the availability of appropriate community-based post-diagnostic support, the availability of resources attached to the diagnostic services and clinician own preferences. The results highlight the need to develop a single integrated framework that provides a blueprint for supporting the person, from concern about cognition to assessment and diagnosis, through to post-diagnostic support.

In the final question of the survey, clinicians identify some of the key components necessary for a good dementia diagnostic service, from referral to assessment, disclosure and post-diagnostic support. These core elements will inform the development of a national dementia diagnostic and post-diagnostic framework for Ireland.

10. Conclusion

This survey has added to the growing body of knowledge and evidence collected to inform the development of a dementia diagnostic and post-diagnostic framework for Ireland. Together with the Review of Memory Clinics, the Dementia Diagnostic Service for Ireland: A Literature Review (2018) and Dementia Post-diagnostic Support for People with Dementia and their Carers: Literature Review (2018) the evidence from this survey gives us vital information to ensure that the framework developed will be suitable and adaptable to current structures, and will allow us to cost the development of resources and services to meet national minimum standards for dementia diagnosis in Ireland.

11. References

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