Dementia Diagnosis Clinics

A survey of the models throughout Scotland

Summary of findings

August 2023

Contents

Purpose

As part of Healthcare Improvement Scotland's dementia improvement work and in association with the Post-Diagnostic Support (PDS) Leads network, we wished to identify different clinic models in place across Scotland to diagnose dementia. This work would complement the census conducted in November 2021 by Brain Health Scotland and Alzheimer Scotland: "A Scoping Exercise of Clinical Assessment and Management of Cognitive Complaints and Neurodegenerative Disease in Scotland".

We wanted to learn:

- the details of who assesses
- how this is carried out, and
- who delivers the diagnosis.

Method

We issued an online survey to capture this information.

We piloted the survey in August 2022. Following the pilot, we made minor amendments to the questionnaire.

The survey was issued in September 2022. The survey was issued to post-diagnostic support leads who were asked to facilitate completion amongst the relevant stakeholders within their Health and Social Care Partnership (HSCP). The survey closed in December 2022.

Key findings

The survey results showed:

- The majority of dementia diagnostic assessments take place in Older Adult Community Mental Health services
- A variety of professionals from mental health teams contribute towards diagnostic assessment.
- There is a wide variation in how different teams allocate the new referrals and how diagnosis is arrived at and delivered. This may contribute towards variations in waiting lists however we were unable to go into detail.
- Psychiatrists appear to play a key part in the diagnosis of dementia followed by geriatricians and psychologists.
- Most of the services rely on psychiatrists to deliver the diagnosis.

- Long waiting times to access memory services and imaging services appear to be the major barriers in making timely diagnosis.

- People are seen at mild to moderate stages of dementia to make a diagnosis rather than at late or advanced stages. This appears to be an improvement.

- Memory clinics/services do not formally encourage people to come forward for diagnosis or seek formal feedback on the service.

Response and analysis

We included responses from both the pilot survey and the main survey in our analysis. Respondents were from a variety of services including:

- Memory Clinics

- Mental Health Assessment Teams, and

- Older People's Mental Health Teams.

We checked for any gaps in service name and areas to ensure we had this information to calculate our response rate. We also checked for duplicate responses from individual services.

We received 33 responses in total. The responses represent services within 28 of 31 HSCPs. The response rate is shown in the table below.

| Response rate	Number
Total responses	**33**
Survey	29
Pilot	4
Responses by HSCPs	**28 of 31**

Themes

In this overview, we share five themes identified in our analysis.

1. A range of professions are involved in diagnostic assessments

- Our survey found that a range of professions are involved in diagnostic assessments. The most common professions involved in diagnostic assessments are listed below.

- Community mental health nurses (32 of 33 respondents).

- Psychiatrists – both consultant psychiatrists (31 respondents) and other grade psychiatrists (22 respondents).

- Occupational therapists (23 respondents).

- Psychologists or neuropsychologists (22 respondents).

Who contributes to the diagnostic assessments in the service?
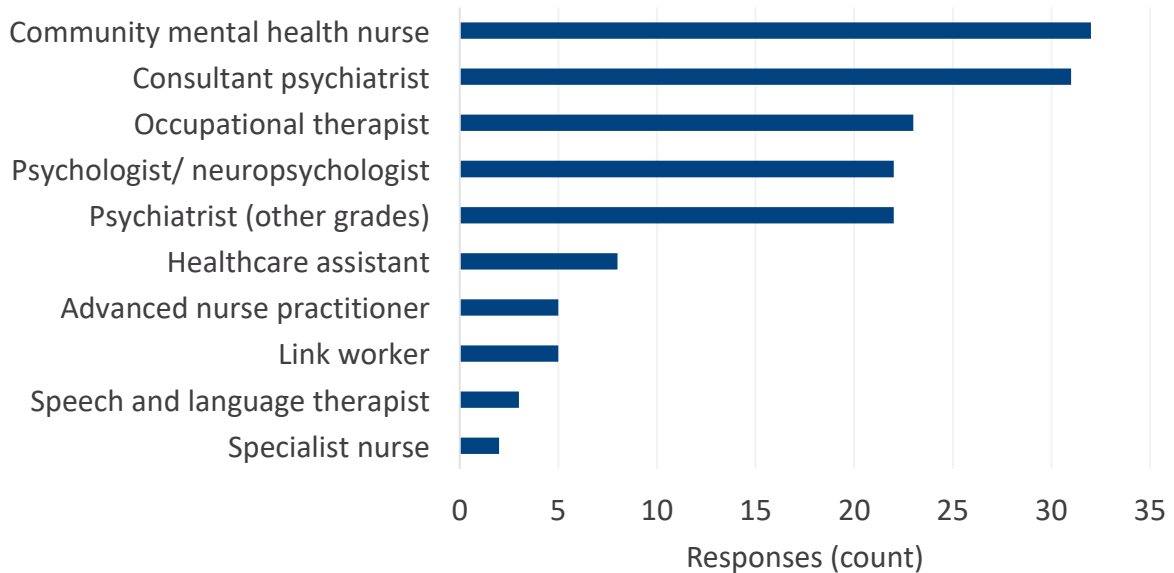
The survey also explored how new referrals are allocated. Our findings suggest that new referrals are seen by different members of staff depending on each service's process.

- New referrals are allocated to different members of the multi-disciplinary team based on their needs (14 responses). This is where the person is allocated to different members of the team to conduct assessments and a diagnosis will then be made by the multi-disciplinary team.

- New referrals are seen by members of staff assisting the diagnosis service before being seen by the psychiatrist (13 responses). This is where members assisting the process of diagnosis conduct assessments that contribute to making the diagnosis before the person is seen by the psychiatrist.

How are new referrals allocated?
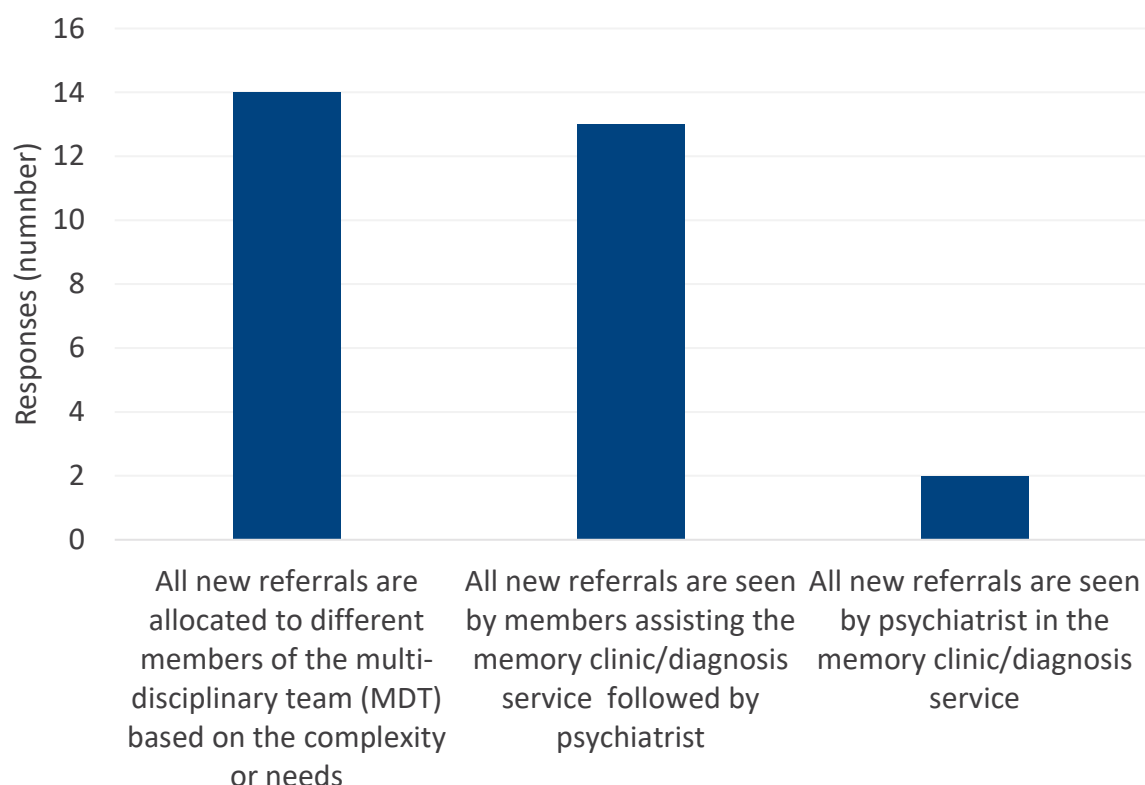
We asked our respondents if they had criteria in place to indicate whether particular assessments were required as part of the diagnostic process.

- Twelve respondents indicated that they had criteria to highlight cases requiring a psychiatrist to carry out assessment and diagnosis.

- Nine respondents indicated that they had criteria to highlight complex cases requiring neuropsychological assessment as part of the diagnostic process.

2.   Within many services psychiatrists are a key part of the diagnostic process

Our survey findings suggest that psychiatrists are a key part of the diagnostic process for many services.

We found that psychiatrists are usually involved in making a diagnosis. 32 respondents said a psychiatrist was always or often involved in making the diagnosis.

However, there was evidence that other professions are also involved. Our survey found examples where geriatricians, psychologists, neurologists and GPs were involved in making a diagnosis.

Please tell us which of the following professionals make the diagnosis in your HSCP?
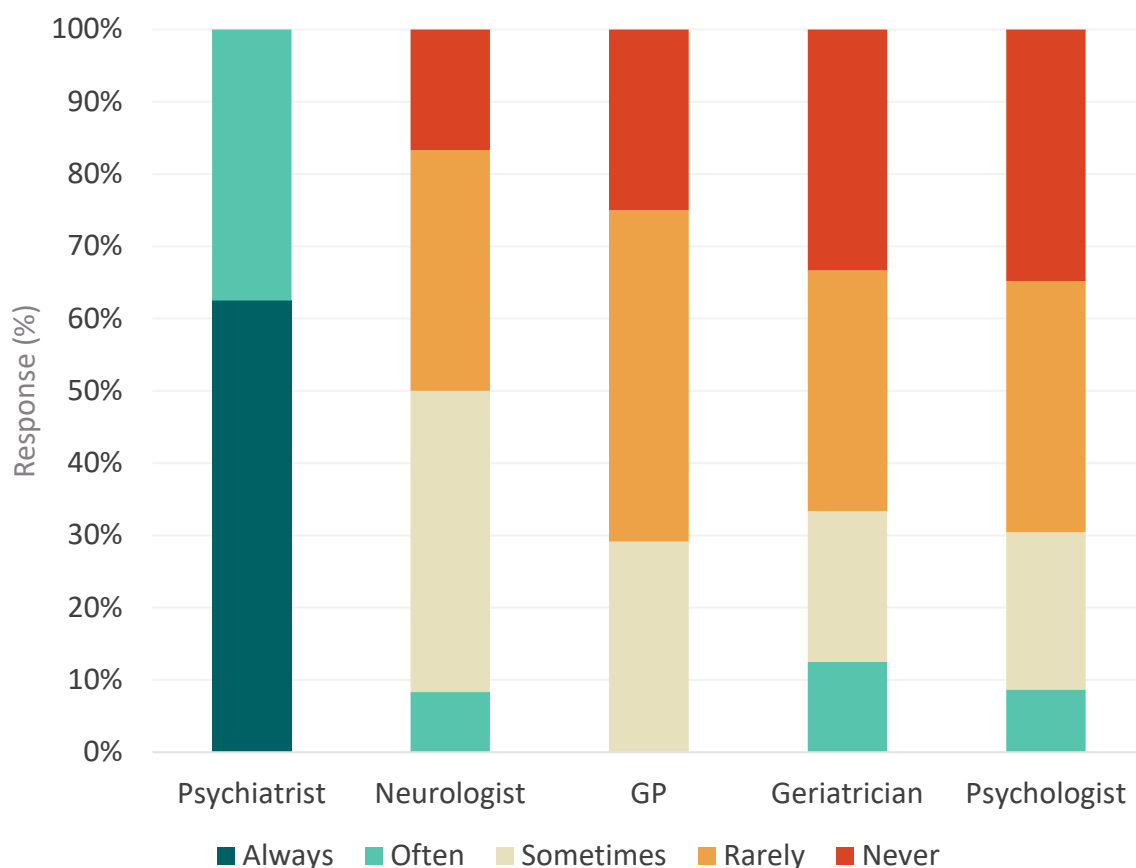

Our survey asked how the diagnosis was arrived at in their setting. The most common answers listed below indicate that psychiatrists are key in making a diagnosis.

- 27 responses stated that diagnosis is made by a psychiatrist after reviewing the diagnostic information from staff assisting the memory clinic followed by meeting the patient.

- 15 responses stated that diagnosis is made by a psychiatrist after undertaking full assessment of the patient at the visit.

When responding to this question, respondents could select more than one model. Nearly half of respondents (16 respondents) selected more than one answer indicating that there is more than one model in place in their service.

How is the diagnosis arrived at in your setting?
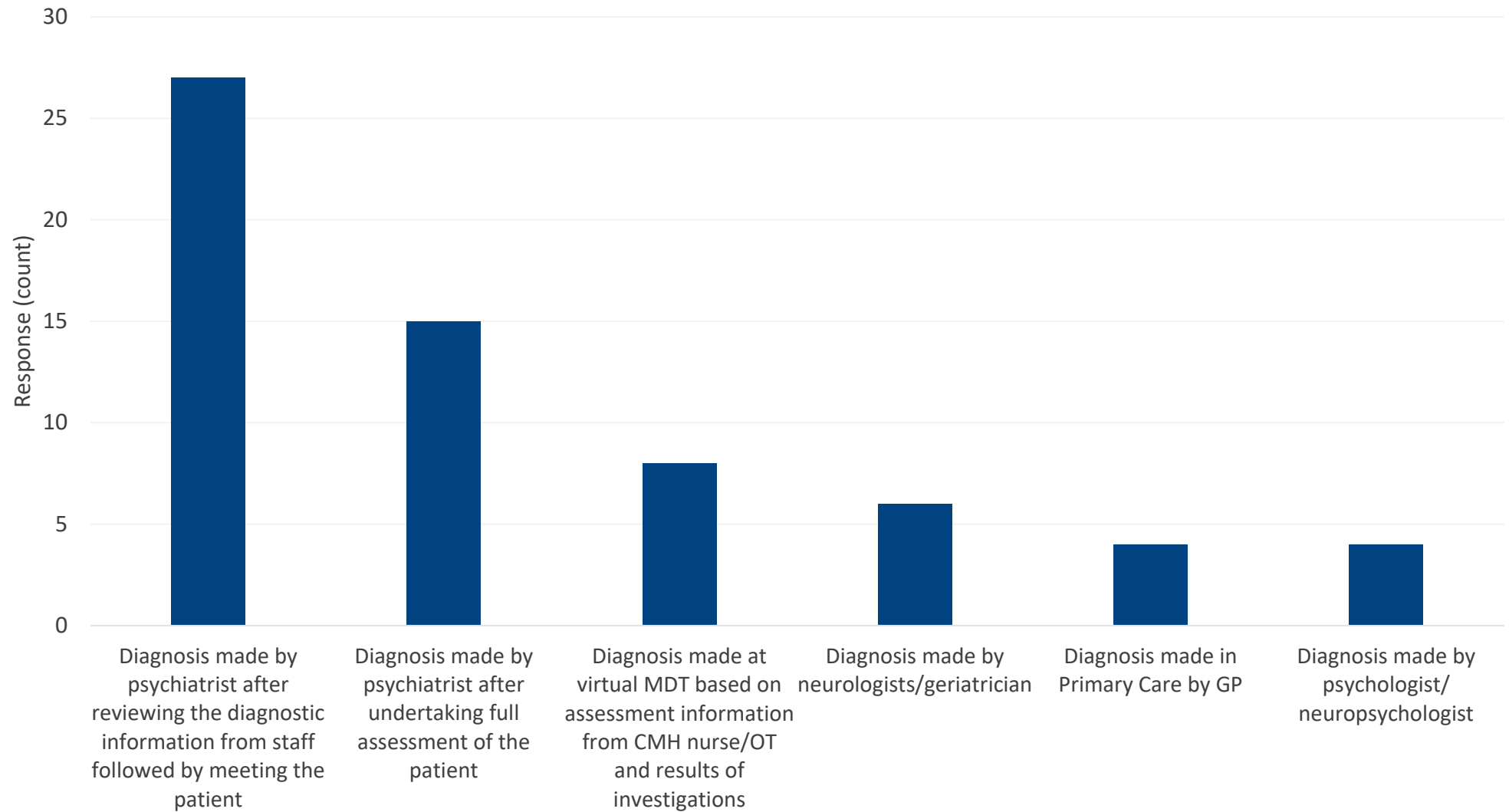
We also asked which staff were involved in delivering a diagnosis. The most common responses (listed below) suggest that psychiatrists were typically involved in delivering the diagnosis.

- Eight respondents said the psychiatrist exclusively delivered the diagnosis.

- A further 19 respondents said the psychiatrist usually delivered the diagnosis with other health care professionals occasionally.

In your service or similar setting, who is involved in delivering the diagnosis to the person and their family/carer(s)?
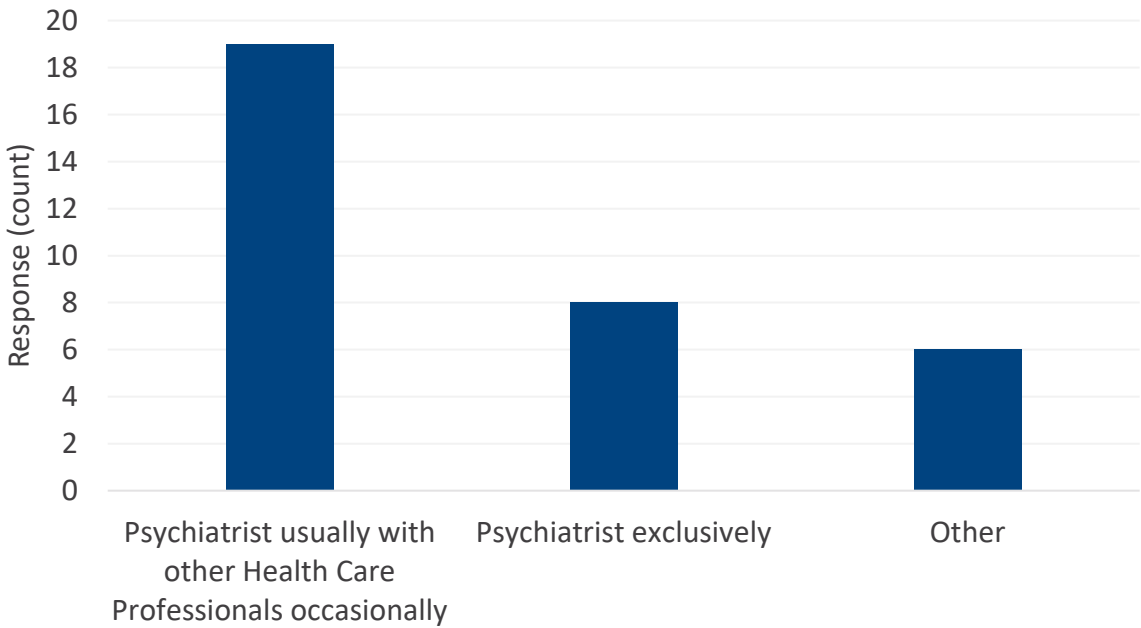
3. People with dementia are often diagnosed within the Older People's Mental Health Team

Our survey asked about where people are assessed and diagnosed.

We asked how often people were diagnosed in different settings. Our survey found that people were most often diagnosed within the Older People's Mental Health Team. 30 respondents reported that people were "very often" diagnosed within the Older People's Mental Health Team.

However, there were examples of diagnoses within other settings. For example, 14 respondents said people were "often" or "very often" diagnosed at home.

How often do you think people are diagnosed in these settings in your area?

Legend: ■ Very often ■ Often ■ Sometimes ■ Rarely ■ Never

Y-axis: Response (%)

X-axis categories: Older People's Mental Health Team (this includes your memory clinic); Person's own home; Care home; Acute hospital; Community hospital/step down bedded care provided by NHS/HSCP; GP practice/ primary care; Learning disability service; Adult mental health service; Social services
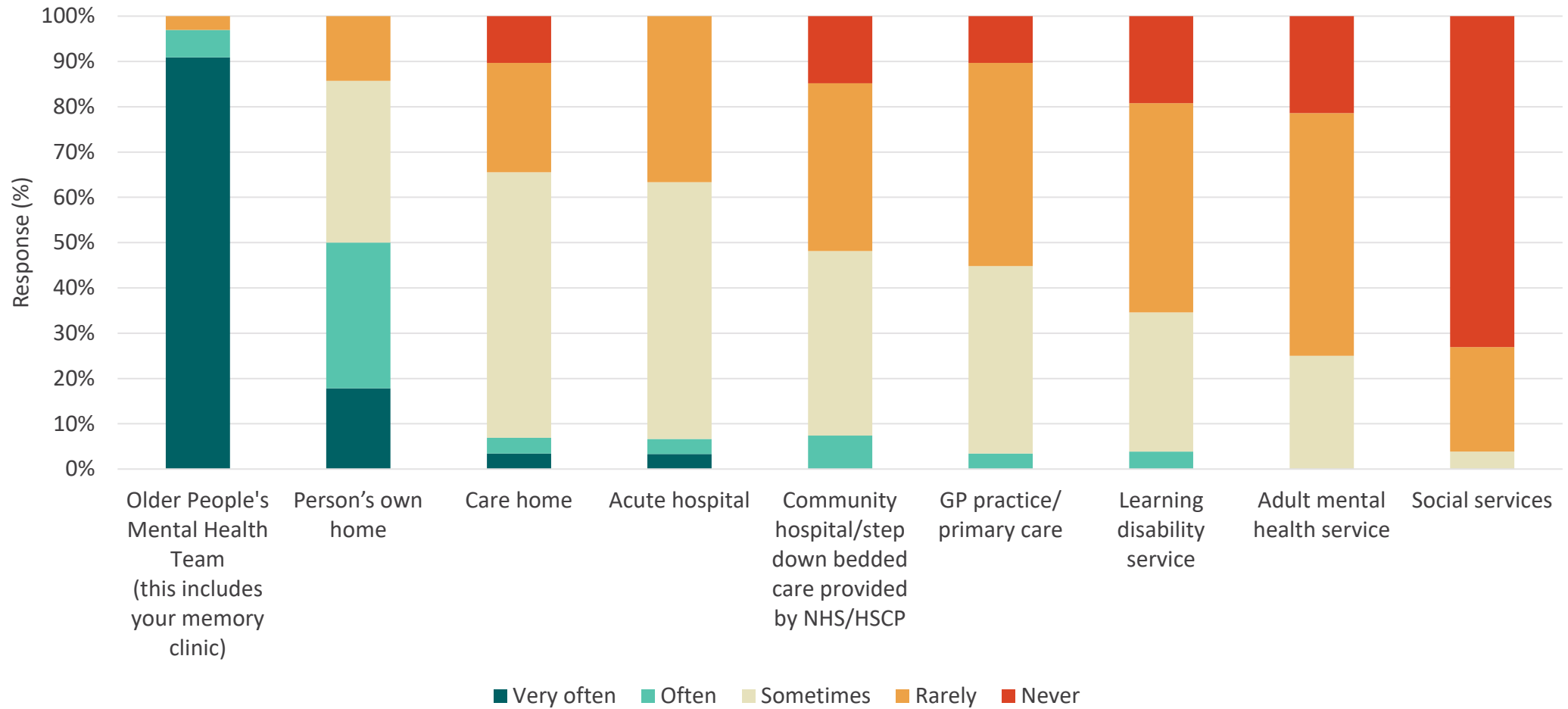
Respondents were also asked about the proportion of assessments conducted virtually. Our finding suggested that few initial assessments are conducted virtually. 26 respondents said that less than 10% of initial assessments are being done virtually by video or phone in their service.

## 4. Waiting times can be a barrier to accessing services

Our survey collected information about waiting times.

Nineteen respondents stated that they collected data on waiting times for assessment and diagnosis. Fifteen respondents provided information on their waiting list. The length of waiting list ranged from1 week to 40 weeks.

Our respondents indicated that they found waiting lists were a barrier to accessing their service. The survey asked respondents to identify the greatest barriers to people in your service area receiving a timely diagnosis at present. Respondents were asked to select up to two responses. Four options were provided. Respondents could also provide an "other" response, or select no barriers. The most commonly identified barriers are listed below and relate to waiting lists.

- 21 respondents indicated that memory clinic/diagnosis service waiting times were a barrier.

- 19 respondents indicated that brain scan waiting times were a barrier.

In your view, what are the greatest barriers to people in your service area receiving a timely diagnosis at present?
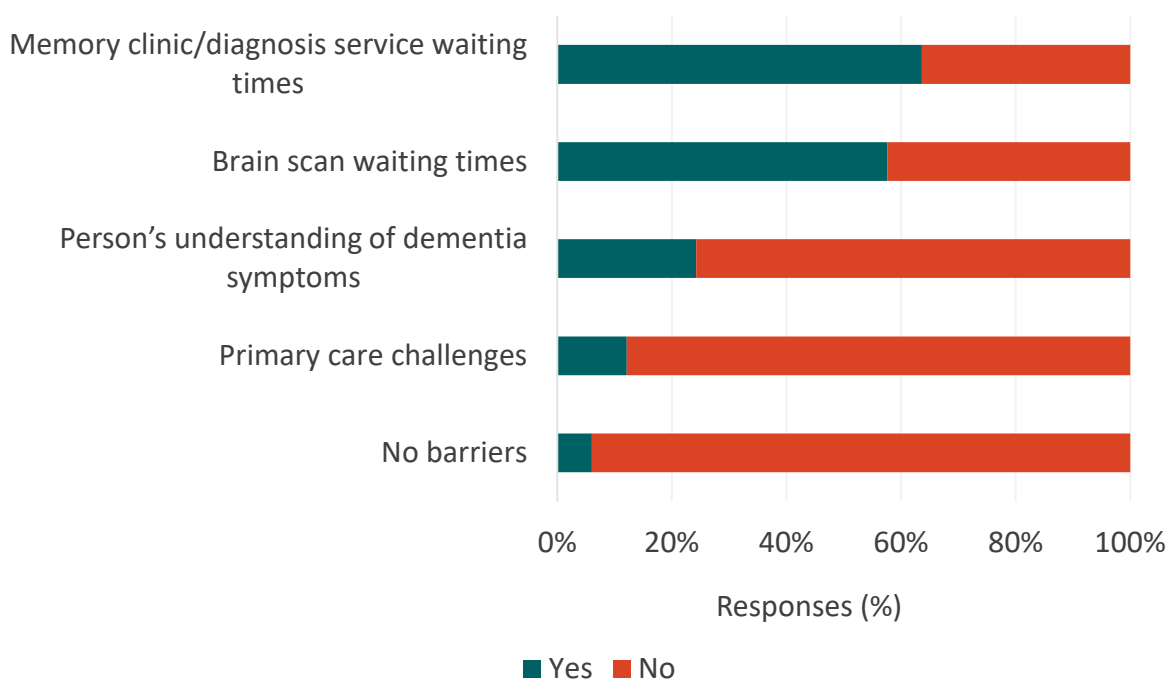
5. People are most commonly diagnosed in the mild and moderate stages of dementia

The survey asked what stage of dementia people are typically diagnosed. Our respondents indicated that people with dementia are most often diagnosed in the mild and moderate stages of dementia in their services.

- 30 respondents indicated that people with dementia were often or very often diagnosed in the moderate stages of their dementia.

- 21 respondents indicated that people with dementia were often or very often diagnosed in the mild stages of their dementia. This figure includes 10 respondents who indicated that people were "very often" diagnosed in the mild stages of their dementia.

Please give an indication of how often people in your memory service/diagnostic service are diagnosed in the:
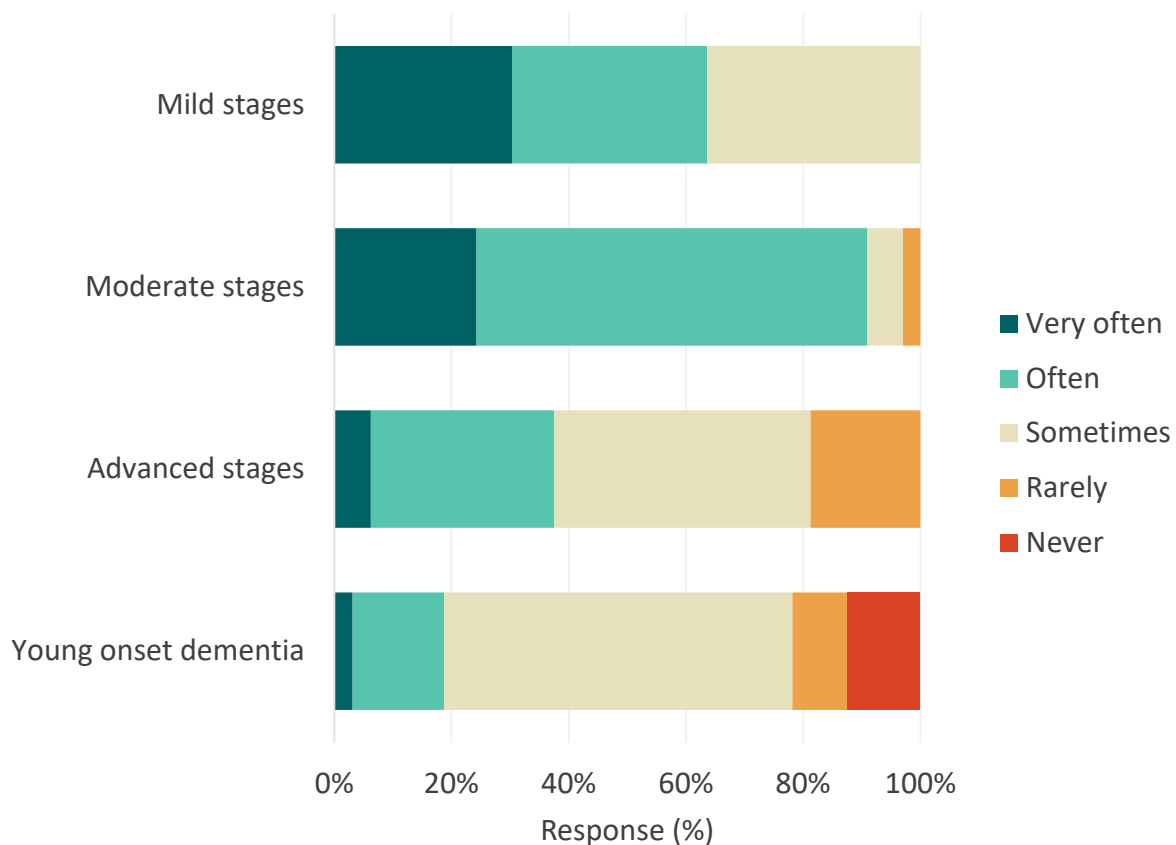
Our survey asked whether services encourage people to come forward for earlier diagnosis and the support offered pre-diagnosis.

We asked respondents about action they took to encourage people to come forward for earlier diagnosis. 16 services discussed action they took to support people to come forward earlier for diagnosis. Examples given included:

- promotion activities

- working with community groups, or

- working with GPs or primary care.

Ten respondents indicated that they offer pre-diagnostic counselling.

Using the information in this survey

The findings from this survey should be considered by services who wish to improve their approaches and processes when diagnosing dementia. The findings should also be considered by Scottish Government Dementia Policy in relation to developing and progressing Dementia Strategy work plans to ensure people receive a timely diagnosis of dementia.

Further information

For more information, please contact his.focusondementia@nhs.scot.

Appendix – Data tables

Who contributes to the diagnostic assessments in the memory clinic/diagnosis service?	Count
Community mental health nurse	32
Consultant psychiatrist	31
Occupational therapist	23
Psychiatrist (other grades)	22
Psychologist/ neuropsychologist	22
Healthcare assistant	8
Link worker	5
Advanced nurse practitioner	5
Speech and language therapist	3
Specialist nurse	2
Base	**33**

Do you run a one stop to diagnosis model?	Count
Yes	5
No	28
Total	**33**

In an average month where do referrals come from?	Very often	Often	Sometimes	Rarely	Never	Base
GP practice/primary care	27	2	2	1	1	33
Acute hospital	1	2	23	5	1	32
Adult mental health service	2	0	14	12	2	30
Care home	2	4	10	8	6	30
Social services	2	4	8	8	9	31
Community hospital/step down bedded care	1	1	7	9	3	21
Learning disability service	0	0	2	14	11	27
Self-referral	0	0	2	7	18	27

Do you collect data on the waiting times for assessment and diagnosis?	Count
Yes	19
No	14
Base	33

In your view, what are the greatest barriers to people in your service area receiving a timely diagnosis at present?	Yes	No	Total
Memory clinic/diagnosis service waiting times	21	12	**33**
Brain scan waiting times	19	14	**33**
Person's understanding of dementia symptoms	8	25	**33**
Primary care challenges	4	29	**33**
No barriers	2	31	**33**

How are new referrals allocated?	Count
All new referrals are allocated to different members of the multi-disciplinary team (MDT) based on the complexity or needs	14
All new referrals are seen by members assisting the memory clinic/diagnosis service followed by psychiatrist	13
All new referrals are seen by psychiatrist in the memory clinic/diagnosis service	2
Other	4
Total	**33**

Please tell us which of the following professionals make the diagnosis in your HSCP?	Always	Often	Sometimes	Rarely	Never	Base
Psychiatrist	20	12	0	0	0	32
Neurologist	0	2	10	8	4	24
General practitioner	0	0	7	11	6	24
Geriatrician	0	3	5	8	8	24
Psychologist	0	2	5	8	8	23

How is the diagnosis arrived at in your setting?	Yes	No	Total
Diagnosis made by psychiatrist after reviewing the diagnostic information from staff assisting the memory clinic followed by meeting the patient	27	6	**33**
Diagnosis made by psychiatrist after undertaking full assessment of the patient at the clinic/visit	15	18	**33**
Diagnosis made at virtual MDT based on assessment information from Community Mental Health Nurse or Occupational Therapist and results of investigations	8	25	**33**
Diagnosis made by neurologists/geriatrician	6	27	**33**
Diagnosis made in Primary Care by General Practitioner	4	29	**33**
Diagnosis made by psychologist/neuropsychologist	4	29	**33**

How are new referrals allocated?	Count
Psychiatrist usually with other Health Care Professionals occasionally	19
Psychiatrist exclusively	8
Others (Health Care Professionals involved at assessment stage)	2
Other	4
Total	**33**

How often do you think people are diagnosed in these settings in your area? (This is where the actual diagnosis is arrived at and shared with the person/their family)	Very often	Often	Sometimes	Rarely	Never	Total
Older People's Mental Health Team	30	2	0	1	0	**33**
Person's own home	5	9	10	4	0	**28**
Care home	1	1	17	7	3	**29**
Acute hospital	1	1	17	11	0	**30**
Community hospital/step down bedded care provided by NHS/HSCP	0	2	11	10	4	**27**
GP practice/primary care	0	1	12	13	3	**29**
Learning disability service	0	1	8	12	5	**26**
Adult mental health service	0	0	7	15	6	**28**
Social services	0	0	1	6	19	**26**

What cognitive assessment tools are used in your memory clinic/diagnosis service? Tick all that apply:	Count
ACE3	32
MOCA or blind MOCA	26
In-depth neuropsychological assessment	20
AMPS	14
LACLS	12
MMSE	10
IQCODE	8
Other	8
Base	**33**

What proportion of initial assessments are being done virtually (by video or phone) in your service?	Count
Less than 10%	26
Less than 25%	3
Less than 50%	2
Don't know	2
Total	**33**

Standard operating procedures and criteria	Yes	No	Base
Do you have specific standard operating procedures, pathways or processes that guide the process of assessment and diagnosis?	22	10	**32**
Do you have specific referral criteria for the consideration of dementia assessment or diagnosis?	21	12	**33**
Do you have criteria to indicate a complex case requiring a psychiatrist to carry out assessment and diagnosis? How is this decision made and implemented, and by whom?	12	19	**31**
Do you have criteria to indicate a complex case requiring neuropsychological assessment as part of the diagnostic process?	9	23	**32**

Please give an indication of how often people in your service are diagnosed in the:	Very often	Often	Sometimes	Rarely	Never	Base
Mild stages	10	11	12	0	0	**33**
Moderate stages	8	22	2	1	0	**33**
Advanced stages	2	10	14	6	0	**32**
Young onset dementia	1	5	19	3	4	**32**
Please give an indication of how often a specific diagnosis is made and given to the person (rather than a diagnosis of 'unspecified dementia').	20	9	2	0	0	**31**

Does your service offer pre-diagnostic counselling?	Count
Yes	10
No	22
Total	**32**

Do you seek feedback from families and carers on their experience of the assessment and diagnostic process?	Count
Yes	18
No	15
Total	**33**

Do you have a specific pathway or process, or provide a specific service to support equitable access to diagnosis for the following groups?	Yes	Data collected
People under the age of 65	13	7
People who live in care homes	13	6
People with deaf/blindness	11	2
People from minority ethnic groups	6	2
People whose first language is not English	6	2
People who live in an area of deprivation	5	1
People with learning disability	4	2
People with a minority sexual orientation	4	3
People who have undertaken or are undertaking or considering gender reassignment	4	2
Other	1	0

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or email his.contactpublicinvolvement@nhs.scot

Healthcare Improvement Scotland

Edinburgh Office
Gyle Square
1 South Gyle Crescent
Edinburgh
EH12 9EB

Glasgow Office
Delta House
50 West Nile Street
Glasgow
G1 2NP

0131 623 4300

0141 225 6999

www.healthcareimprovementscotland.org