A Scoping Exercise of Clinical Assessment and Management of Cognitive Complaints and Neurodegenerative Disease in Scotland

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Executive Summary

→ The Scottish Cognitive Clinics Scoping Exercise was conducted from January to September of 2021. The scoping exercise aimed to collate information on the current landscape for clinical assessment of cognitive complaints and neurodegenerative disease in Scotland.

→ The scoping exercise consisted of an examination of public information ('secondary data': academic and 'grey' literature, NHS Scotland health board websites, Freedom of Information Requests), and analysis of novel data generated through a benchmarking survey of current services (the Scottish Cognitive Clinics Census). To mitigate for the impact of the COVID-19 pandemic, clinics were asked to respond to the census as would have been accurate in 2019.

→ Literature on memory clinics, including previously published surveys of these services, indicated that clinical services for the assessment of cognitive complaints have arisen sporadically, resulting in a non-uniform approach to service provision. This appears to be the case in Scotland and internationally.

→ Freedom of Information responses indicated there were approximately 58 clinical services for assessing cognitive complaints across thirteen of the fourteen health boards in Scotland. One of these health boards advised that they do have a service, but did not provide specific details. The remaining health board reported that there were no relevant services within their region.

→ Health board websites varied in the information made available, and the ease of access to relevant information. Largely, health board websites provided generic information summarising the characteristic symptoms and behaviours associated with a dementia syndrome. Occasionally, websites described disease pathology and provided signposting for post-diagnostic support information. Overall, these websites were difficult to navigate, and rarely provided region-specific information.

→ The Scottish Cognitive Clinics Census received 43 valid responses. At least one valid response was received from each of the fourteen health boards, and at least one valid response was received from 28 of the 32 Local Authority areas (87.5%).

→ Summary statistics from the Scottish Cognitive Clinics Census (2021) include:

- 74.4% of services were in urban areas; 60.5% were in more deprived areas.
- Services most often described themselves as Community Mental Health Teams (48.8%), 'memory clinic/cognitive clinic/dementia services' (18.6%), or Psychiatry Outpatient Clinics (16.3%).
- Most common staff types included Psychiatrist (93%), Nurse (81.4%), and Occupational Therapist (60%).

- Alzheimer's Disease was most frequently described as a 'very common' diagnosis (62.8%), followed by Vascular Dementia (53.5%), and Mixed Dementias (52.4%). Mild Cognitive Impairment was most frequently described as 'common' (44.2% of services; 'very common' in 37.2% of services).

- Patients were most commonly in the 75-84 years age group (72.1% of services).

- A majority of clinics (60%) provided a first appointment for the patient within eight weeks or less of receiving a referral (up to four weeks = 25%, up to eight weeks = 35%).

- The median proportion of patients referred for brain imaging was 70% (range: 10% - 100%), for cerebrospinal fluid testing was 0% (range: 0% - 25%), and for genetic testing was 1% (range: 0% - 50%).

- The median proportion of patients receiving cognitive enhancer medications was 60% (range: 0% - 97%).

- 81.4% of responding services reported engaging in some form of research activity.

→ Overall, there appears to be significant variation in clinical service provision across Scotland. These findings are comparable with similar surveys and public information evaluations available in the literature from the broader United Kingdom and internationally.

→ Future iterations of the Scottish Cognitive Clinics Census and of other aspects of the present scoping exercise would enable analysis of longitudinal trends in service provision in Scotland.

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Definitions and Abbreviations

Definitions

Cognitive complaints

Clinically evident, mild, and/or subjective concerns relating to an individual's cognitive performance, raised by the individual themselves, those close to the individual, or by healthcare professionals. This may include poor performance on cognitive testing, biomarker evidence of neurodegenerative disease, or patient history indicating of a decline in cognitive functioning.

Biomarkers

Indicators of pathologies (disease processes) which may be present even in the absence of apparent symptoms. For example, brain imaging biomarkers (brain scans, such as MRI scans) might include evidence of cerebral atrophy (brain tissue shrinkage) or cerebrovascular disease (damage to blood vessels of the brain), even while cognitive testing and patient history may not indicate any symptoms of confusion, memory loss, or changes in behaviour.

Neurodegenerative diseases

Disease processes affecting the health of the brain, resulting in the death of brain cells. These disease processes may arise from one or a combination of inherited (genetic) traits, factors relating to how we live our lives (e.g., physical inactivity, smoking, alcohol and drug use), brain injury or trauma (e.g., head injury, lack of oxygen), or disruption of the blood supply to the brain (e.g., ischaemic stroke, small vessel disease). In the current scoping exercise, we focus on neurodegenerative diseases such as Alzheimer's Disease and related pathologies which give rise to primary clinical dementia syndromes (e.g., Alzheimer's dementia, vascular dementia, dementia with Lewy Bodies, frontotemporal dementia), rather than secondary dementias (e.g., dementias arising from predominantly 'motor' disorders such as Parkinson's Disease, Multiple Sclerosis, or Huntington's Disease, or from infectious diseases, such as HIV).

Memory Clinics/Cognitive Clinics/Dementia Services

Health care services providing clinical assessment for individuals with cognitive complaints and/or suspected neurodegenerative diseases. These are typically secondary care services (requiring a referral from a general practitioner – family doctor – or other healthcare professional), and may be provided in hospital, community, or domestic settings.

Abbreviations

AChEI: Acetylcholinesterase Inhibitors; **AD**: Alzheimer's Disease; **AlzScot**: Alzheimer Scotland; **ARUK**: Alzheimer's Research UK; **CMHN**: Community Mental Health Nurse; **CMHT**: Community Mental Health Team; **CSF**: Cerebrospinal Fluid; **FDA**: (United States) Food and Drug Administration; **FOI**: Freedom of Information; **JDR**: Join Dementia Research (participant register); **MCI**: Mild Cognitive Impairment; **MSNAP**: Memory Service National Audit Programme; **NHS**: National Health Service; **RCPsych**: Royal College of Psychiatrists.

1. Introduction

1.1. Background

Cognitive ('Memory') clinics were established sporadically across Scotland in the latter half of the 20th Century to provide assessment and treatment for individuals with a clinical dementia syndrome. Cognitive clinics, also referred to as memory clinics and dementia services, became more common in the 1990s to early 2000s, following the approval of Acetylcholinesterase Inhibitors (AChEIs) and Memantine for symptomatic treatment of clinical dementia syndromes[1]. These clinics typically arose as the result of the special interest of individual clinicians or clinical academic groups, as opposed to a more uniform implementation across Scotland. The sporadic nature of their establishment has led to considerable variability (heterogeneity) of clinical services provided across the fourteen Scottish health boards[2], and there is very little centrally held or publicly available information about how Scottish cognitive clinics and dementia services currently operate.

1.2. Surveying Cognitive Clinics Internationally and in Scotland

A literature review identified a small number of detailed survey and audit methodologies and results from cognitive clinics in New Zealand[3], the Netherlands[4], Northern France[5], the British Isles[6], England[7], London[8], and Scotland[2]. These surveys and audits typically assess staff and patient demographics, regional information, referral criteria, and clinical investigations.

The 2007 survey of memory clinics in New Zealand[3] was a brief structured questionnaire, completed by the clinic's lead clinician. This survey identified eight memory clinics in New Zealand, which were funded equally by mental health services and by geriatric medicine. Common clinic lead staff types included psychogeriatricians, geriatricians, psychologists. The most commonly used cognitive assessment were the mini-mental state examination (MMSE), a clock drawing task, and the Cambridge Cognitive Examination. Authors noted variability in service provision across medium and smaller district health boards.

A recent (2019) paper on 'The development of memory clinics in the Netherlands over the last 20 years'[4] analysed longitudinal memory clinic survey data. Surveys were conducted in 1998, 2004, 2009, and 2017. Authors found that the number of memory clinics increased greatly from twelve clinics in 1998 to 91 in 2016, with capacity increasing from 1560 patients to 24,388 patients. Further data were obtained on diagnostic tools used and proportion of patients referred for specialist diagnostics. Authors noted significant variation in the number of patients referred for specialist diagnostics across memory clinics.

A similar study of 'Twenty-year trends in patient referrals throughout the creation and development of a regional memory clinic network' from Northern France (2020)[5] identified comparable trends from 1997 to 2016 as were seen in the Netherlands' study. In a memory clinic network in Northern France, clinic numbers increased from twelve in 1997 to 29 in 2016. Authors found the regional memory clinic network led to increased referrals for vulnerable patients, and that the oldest patients were referred earlier in the disease process.

The second 'Leicester survey' of memory clinics in the British Isles[6] (2002) built upon an earlier (1993) questionnaire. The second survey received 72 replies, 58 of which were from active clinics. As with more recent studies, the authors identified an increase in memory clinic provision from 1993 to 2002. While the authors of this survey report services to be "similar in many aspects of their functioning", they concede that as the memory clinic model moves from predominantly an academic endeavour into mainstream clinical services, there could be benefit in greater coordination and the development of a core dataset for assessment.

A survey of 73 memory assessment services in England in 2015[7] found "considerable variation" in staff numbers, new patients per staff, and nurse:doctor ratios. The authors also noted differences in operational performance, with disparity identified in length of first appointment, length of time to first follow-up, and frequency of follow-up appointments offered.

A 2019 report on the London Memory Service Audit and Quality Improvement Programme[8] describes audits of ten memory services in London. As with the above surveys, authors of this audit programme found variation in referrals for neuroimaging and neuropsychological services, diagnosis subtypes, waiting times, and post-diagnostic support. The authors recommend the streamlining of memory clinic pathways, and improved adherence to the National Institute for Health and Care Excellence (NICE) guidelines for dementia assessment.

Finally, the 2008 survey of Scottish memory clinics[2] provides us with the most recent benchmark of service provision in Scotland. 34 replies were received, with one from each mainland health board. It was determined that the island health boards (Western Isles, Orkney, and Shetland) did not have a formal memory clinic at this time. Of all respondents, eighteen confirmed that they provided a current memory clinic service. The author found "considerable variation" in memory clinic practice across the country, with differences identified in clinic characteristics, assessment techniques, and approaches to treatment. The author reported that clinicians appeared to rely on their own clinical judgement as opposed to national clinical guidelines.

1.3. Preparedness for early disease detection and disease-modifying therapy

A recent report co-produced by the Royal College of Psychiatrists (RCPsych) and Alzheimer's Research UK (ARUK) – *'Are we ready to deliver disease modifying treatments?'*[9] – presented key findings including that a very small proportion (6%) of psychiatry services are able to fully meet NICE guidelines relating to biomarker and diagnostic tests, that a clear diagnostic framework is lacking, resulting in clinical inconsistencies. Recommendations from this report included, among others, that the NHS should dedicate funding to the improvement of diagnostic infrastructure and that the NHS should commission a clinical pathway for improving access to a disease modifying therapy. These recommendations align with previously presented recommendations of the (2017) Edinburgh Consensus[10], which outlined the likelihood of disease-modifying therapies being effective at earlier disease stages and noted that current service provision is unlikely able to accommodate novel disease-modifying therapies, recommending an optimised care pathway, education and training for primary and secondary care, and ensuring a standardised nationwide approach to assessment and management.

During the course of this scoping exercise, the United States Food and Drug Administration (FDA) approved (with some caveats) the first disease-modifying therapy for the treatment of early-stage Alzheimer's Disease (AD)[11]. These long-awaited developments in the development of disease modifying therapies, alongside the growing consensus regarding the value of biomarker use for early disease detection, further emphasise the importance of the present evaluation of the current landscape of clinical services in Scotland.

1.4. Scoping Exercise Aim

This scoping exercise, conducted from January to September of 2021, aims to provide a benchmark of current National Health Service (NHS) clinical services in Scotland for the assessment of cognitive complaints and suspected neurodegenerative disease. We intend to clarify the current landscape in Scotland through analysis of public data and a national survey.

2. Stage One: Public Information

2.1. Introduction

Although there is little centrally held public information on the operational aspects of assessing cognitive complaints and neurodegenerative diseases in Scotland, there are well-defined avenues to access region-specific public information. Here, we used Freedom of Information Requests (under the Freedom of Information (Scotland) Act (2002)) and health board websites.

As public authorities, individual health boards can be expected to store and maintain pertinent information on clinical services available within their locales, and can be expected to make this information available to requesting members of the public (with certain exceptions). Broadly speaking, the Freedom of Information (Scotland) Act (2002)[12] compels Scottish public authorities to provide requested information to an applicant, providing the request is reasonable, that the authority holds the information at the time of the request, and that the requested information is not exempt (e.g., due to confidentiality). Providing these conditions are met, the requested information should be provided within twenty working days in ordinary circumstances (amended to 60 working days during the COVID-19 pandemic). Authorities are not required to produce new information, and may provide information already prepared for a previous request if said request was made within a reasonably short timeframe and with considerable overlap of requested information to that of the present request.

NHS Inform (www.nhsinform.scot) is an online platform hosting information about illnesses and conditions, treatment and care, patient and caregiver rights, and a service directory for NHS Scotland clinical services (across primary, secondary, and tertiary care). Alongside NHS Inform, each of the fourteen regional health boards maintain websites hosting information similar to that provided by NHS Inform, but also including information specific to the region.

2.2. Methods

Freedom of Information

We sent an initial Freedom of Information (FOI) request to NHS Scotland, who advised that the information requested was not held centrally and providing contact details for FOI officers in each of the fourteen regional health boards. We subsequently sent requests to each of these health boards, and received responses from all boards within the prescribed timeframe.

We requested a list of cognitive or memory clinics within the health board, and further specified that we were interested in "clinics providing assessment and treatment of cognitive complaints (e.g., dementia services, older adult mental health services)", and for clinic names, locations, and contact details. We did not use the term 'neurodegenerative disease' in this request, as we were aiming to identify services specialising in assessing primary clinical dementia syndromes in this instance. We believed neurological services were deemed more likely to assess patients for related conditions that were not specifically of interest (e.g., Multiple Sclerosis, Motor Neuron Disease, Huntington's Disease, etc.), which may have 'polluted' (or added additional 'noise') to the findings.

We examined FOI responses for a number of characteristics, including number of clinics provided per health board, service type, and mentions of psychiatry, neurology, home visits, post-diagnostic support, young onset, and remote appointment options. Finally, we used postcode information, where provided, to create a map of clinics and team bases in Scotland[13].

Health Board Websites

Data collection from health board websites largely fell into two categories: key word searches and ratings of different categories of information. Key word search terms included "Dementia", "Alzheimer's Disease", "Memory", and "Older Adults Mental Health". We recorded number of results returned ('returns'), and identified how many results within the first five returned items were relevant ('hits'). We categorised the regional specificity of information provided using a semi-quantitative rating scale (described in Table 1) and attributed binary scores (0 – No, 1 – Yes) to whether the health board website provided information about diseases causing dementia, post-diagnostic support, research participation, quality of life, and information for caregivers. We attributed an overall score to each health board (for a total possible score of 13), with items rated consisting of: hits in top 5 returns for key word searches (/4), information specificity rating (/4), and information provided (/5). Characteristics and corresponding ratings for these derived data are summarised in Table 1.

Table 1. Characteristics for semi-quantitative evaluation of health board websites

Characteristic	**Rating**
Key word searches: i) Dementia ii) Alzheimer's disease iii) Memory iv) Older Adults Mental Health	0: No hits in top five returns 1: One or more hits in top five returns *Maximum possible score: 4*
Information specificity	0: No information 1: General information 2: Scotland-specific information 3: Region-specific information 4: Regional information and contact details *Maximum possible score: 4*
Information on: i) Diseases causing dementia ii) Post-diagnostic support iii) Research participation iv) Quality of life (living well with dementia) v) Caregiver support	0: No 1: Yes *Maximum possible score: 5*
	Maximum possible overall score: 13

2.3. Findings

Freedom of Information Requests

We received responses from all fourteen NHS Scotland regional health boards, indicating approximately 58 clinics or services currently provide assessment and/or treatment for cognitive complaints across Scotland. Figure 1 shows a map of clinics or team bases offering assessment for individuals with cognitive complaints in Scotland (in cases where postcodes were provided in the FOI response). Varying approaches to service provision were described. Clinics or services were typically delivered by Older Adults Community Mental Health Teams (CMHTs). In some locations, services are led by Psychiatry, Neurology, or Acute Medicine departments. The type of service provided can broadly be categorised into clinic-based (i.e., clinics operate on a routine basis, with patients attending the clinic; 46% of responses), community-based (i.e., Community mental health nurses – CMHNs – and other CMHT staff provide appointments within GP surgeries and health centres local to the patient; 33% of responses), and a mixed approach, with clinic-based services for certain patient populations (often for Young Onset or complex cases) and a community-based service for typical presentations (21% of responses). A summary of these data is presented in Table 2.

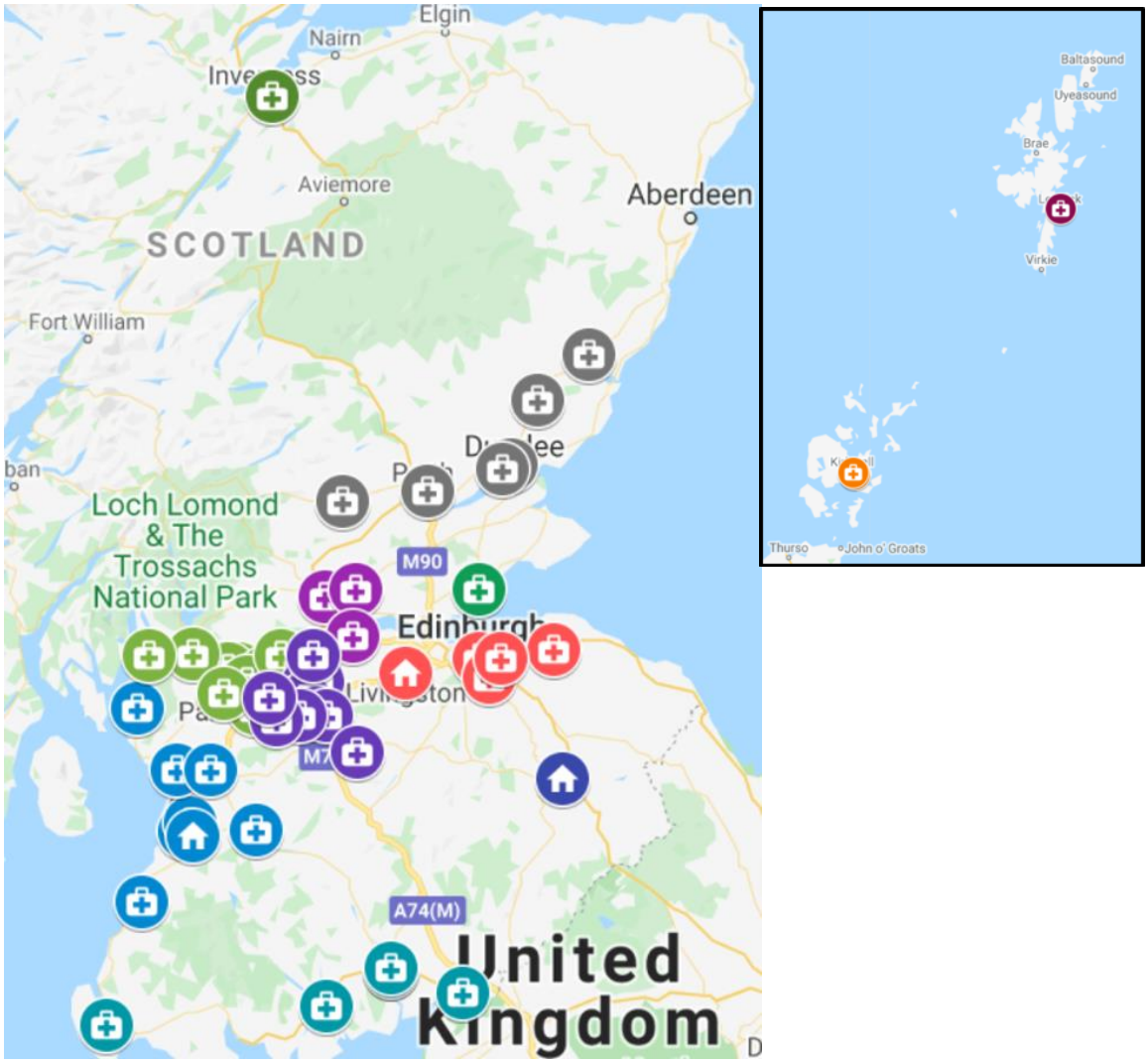

Figure 1. Map of cognitive clinics and team bases in Scotland (2021 FOI responses).

Table 2. Service numbers and types by health board as per FOI responses

NHS Health Board	N Services	Main Service Setting
Ayrshire & Arran	8	Clinic
Borders	1	Community
Dumfries & Galloway	6	Clinic
Fife	3	Mixed
Forth Valley	3	Mixed
Grampian	1	Community
Greater Glasgow & Clyde	12	Mixed
Highland	2	Mixed
Lanarkshire	10	Clinic
Lothian	4	Mixed
Orkney	1	Clinic
Shetland	1	Clinic
Tayside	6	Clinic
Western Isles	0	Not applicable

We evaluated responses for mentions of involvement of psychiatry, involvement of neurology, home visit, post-diagnostic support, young onset services, and remote appointment options. None of these aspects were mentioned by a majority of respondents, but psychiatry was referred to most often (36%). While these specific items were not requested in the initial FOI request, we found that a number of respondents provided additional information above and beyond that which was directly requested. The frequencies with which each of these aspects were referred to are summarised in Table 3.

Table 3. Percentage of responses providing additional information on relevant topics

Topic	Percentage of responses referring to topic
Psychiatry	36% (N = 5)
Neurology	14% (N = 2)
Home visits	21% (N = 3)
Post-diagnostic support	29% (N = 4)
Young onset services	21% (N = 3)
Remote appointment options	29% (N = 4)

Further information relating to regional responses has been presented in a previously prepared report, which can be made available upon request to Brain Health Scotland.

Health Board Websites

We evaluated regional health board websites to determine whether they provide information relating to accessing services for the assessment of cognitive complaints and local support available for individuals living with a dementia diagnosis. Search strategies were kept as simple as possible to reflect ease of access to, and suitability of, information for individuals with minimal digital literacy. As such, more advanced search operators, such as refined search terms ("search term"), wildcard searches (*), combination searches ('and/or' searching), exclusion operators (-), and related search operators (:) were not used in the assessment of returns for key word searches. As outlined above (2.2.), we assigned semi-quantitative ratings for the type and quantity of information provided by health board websites. Overall website ratings are presented in Table 4. Further breakdown of individual aspects of our evaluation are presented in Table 5 (Key word search findings) and Table 6 (information availability and specificity).

Table 4. Overall website semi-quantitative ratings

Health Board	**Website**	**Website score (Max: 13)**
Ayrshire & Arran	www.nhsaaa.net	10
Borders	www.nhsborders.scot.nhs.uk	4
Dumfries & Galloway	www.nhsdg.co.uk	4
Fife	www.nhsfife.org	12
Forth Valley	www.nhsforthvalley.com	8
Grampian	www.nhsgrampian.org	0
Greater Glasgow & Clyde	www.nhsggc.org.uk	7
Highland	www.nhshighland.scot.nhs.uk	6
Lanarkshire	www.nhslanarkshire.scot.nhs.uk	5
Lothian	www.nhslothian.scot	2
Orkney	www.ohb.scot.nhs.uk	0
Shetland	www.shb.scot.nhs.uk	3
Tayside	www.nhstayside.scot.nhs.uk	1
Western Isles	www.wihb.scot.nhs.uk	5

Note. Health board websites were initially accessed and evaluated in March 2021. We accessed sites again to confirm our findings on August 20th, 2021. Information provided through websites may have changed on or after our writing of this report.

Table 5. Health Board Websites: Key Word Search Results (Part 1 of 2).

Health board	Key word search	N Returns	Hits in top 5 (Y/N)
Ayrshire & Arran	Dementia	22	Y
	Alzheimer's disease	96	N
	Memory	11	Y
	Older adults' mental health	956	Y
Borders	Dementia	0	N/A
	Alzheimer's disease	0	N/A
	Memory	0	N/A
	Older adults' mental health	0	N/A
Dumfries & Galloway	Dementia Alzheimer's disease Memory Older adults' mental health	N/A†	N/A
Fife	Dementia	145	Y
	Alzheimer's disease	200	Y
	Memory	33	Y
	Older adults' mental health	1044	Y
Forth Valley	Dementia	21	Y
	Alzheimer's disease	1	N
	Memory	7	Y
	Older adults' mental health	7	Y
Grampian	Dementia	23	N
	Alzheimer's disease	39	N
	Memory	27	N
	Older adults' mental health	38	N
Greater Glasgow & Clyde	Dementia	222	Y
	Alzheimer's disease	0	N/A
	Memory	117	Y
	Older adults' mental health	1	Y
Highland	Dementia	2510	Y
	Alzheimer's disease	103	Y
	Memory	1010	Y
	Older adults' mental health	2180	Y

†No free-text search function provided.

Table 5 Continued. Health Board Websites: Key Word Search Results (Part 2 of 2).

Health board	Key word search	N Returns	Hits in top 5 (Y/N)
Lanarkshire	Dementia	1	N
	Alzheimer's disease	33	Y
	Memory	21	Y
	Older adults' mental health	5	N
Lothian	Dementia	415	Y
	Alzheimer's disease	10	Y
	Memory	228	N
	Older adults' mental health	399	Y
Orkney	Dementia	9	Y
	Alzheimer's disease	17	N
	Memory	1	N
	Older adults' mental health	260	N
Shetland	Dementia	17	N
	Alzheimer's disease	37	N
	Memory	5	Y
	Older adults' mental health	289	N
Tayside	Dementia	18	Y
	Alzheimer's disease	2	N
	Memory	19	N
	Older adults' mental health	3	Y
Western Isles	Dementia	0	N/A
	Alzheimer's disease	0	N/A
	Memory	0	N/A
	Older adults' mental health	0	N/A

Table 6. Information specificity and type provided via health board websites.

Health board	**Specificity** (Max: 4)	**Disease** (Y/N)	**PDS** (Y/N)	**Research** (Y/N)	**QoL** (Y/N)	**Carers** (Y/N)
Ayrshire & Arran	4	Y	Y	N	N	Y
Borders	4	N	N	N	N	N
Dumfries & Galloway	4	N	N	N	N	N
Fife	4	Y	Y	N	Y	Y
Forth Valley	4	N	N	N	N	Y
Grampian	0	N	N	N	N	N
Greater Glasgow & Clyde	2	Y	N	N	Y	N
Highland	2	N	N	N	N	N
Lanarkshire	1	Y	Y	N	Y	Y
Lothian	1	N	N	Y	N	N
Orkney	0	N	N	N	N	N
Shetland	3	N	N	N	N	N
Tayside	0	N	N	Y	N	N
Western Isles	4	N	Y	N	N	N

Note. Specificity score: 0 = No information, 1 = General information, 2 = Scotland-specific information; 3 = Region-specific information; 4 = Region-specific information and contact details; Disease: Information about diseases that cause dementia; PDS: Information about Post Diagnostic Support; Research: Information about research programmes; QoL: Information about Quality of Life (living well with dementia); Carers: Information about support available for caregivers.

Of the fourteen health board websites assessed, the majority provided at least general information about the process of receiving a dementia diagnosis, often linking to or duplicating information provided by the central NHS Inform website. Ease of access to relevant information varied greatly, with some providing information through the website's search function, and others providing information once accessed through 'A-Z of Services' lists. Relevant information was difficult to access, and websites were difficult to navigate, even with a prior knowledge of the clinical pathway for dementia diagnoses in Scotland. It is unlikely that a layperson, particularly a layperson experiencing cognitive difficulties, would be able to access relevant information easily from most health board websites. The NHS Ayrshire & Arran and the NHS Fife health board websites provide examples of good practice for ease of access to a broad range of relevant information.

3. Stage Two: The Scottish Cognitive Clinics Census (2021)

3.1. Introduction

There have been very few surveys or audits of cognitive clinics and dementia services worldwide, let alone of Scottish cognitive clinics. The most recent survey of Scottish cognitive clinics (described here in Section 1: Introduction) was published in 2008[2]. There have been intervention studies (e.g., a 2014 study of three GP surgeries in the Scottish Borders region explored the impact of changing clinical practice from a central 'memory clinic' model to nurse-led older adult mental health team – OAMHT – assessments in rural areas[14]) and observational cohort studies of outcomes of individuals receiving a dementia diagnosis in Scotland[15] in recent years. However, there is still very little descriptive information about the services provided by clinical groups in Scotland seeking to diagnose early neurodegenerative disease and later-stage dementia, whether these are OAMH teams, 'memory clinic' teams, or alternative approaches. This lack of information makes it particularly difficult to determine the standard of care in Scotland, and almost impossible for a patient to understand what they can reasonably expect from their local services.

As a first step in creating a benchmark of clinical services in Scotland, we have conducted a national survey (census) of cognitive clinics. It is hoped that this census may be conducted again in future years, possibly with the addition of clinic audits, to understand how these services continue to develop, particularly in relation to the introduction of disease-modifying therapies and promising advances in early disease detection in clinical practice.

3.2. Methods

Prior to the national rollout of the Scottish Cognitive Clinics Census (2021), we conducted a small pilot run of the first iteration of the census. This version was substantially larger than the final version used in the national rollout, and received poor response rates. Feedback from the pilot study, and scrutiny of which questions clinics were unable to provide responses for, shaped the final version described here.

Previously obtained public data (acquired via Freedom of Information – FOI – requests, described above – Section 2.3) indicated there were 58 relevant clinics/services across twelve of the fourteen Scottish health boards, with one health board reporting they provided a service but offering no detail about number or type of services, and with the remaining health board reporting they did not provide assessment for cognitive complaints. Anecdotal evidence indicated there may be up to 82 relevant services across Scotland, although the exact source of this figure was unclear. Given the complexity of identifying individual services to approach, we recruited clinics/services where we had previously established contact, utilised Alzheimer Scotland's network and resources, and enlisted the Scottish Old Age Psychiatry branch of the Royal College of Psychiatrists to assist in distributing participation information and a link to the census. We requested each of these contacts further distribute the information and census link to colleagues in other Scottish services (i.e., snowball sampling).

To reduce burden on responding clinics, we asked for one response per clinic, and for the responses to be based on the respondent's best estimates and prior knowledge of their service. This was not a formal review or audit of clinic records. The census took approximately ten minutes to complete. No information that could reveal a clinic staff member or patient's identity was requested. Postcodes were requested to identify duplicate responses and to determine the geographical and socioeconomic spread of responding clinics, but were not used to derive any further information (including identifying information) on specific clinics.

We asked three eligibility questions, twenty census questions, and a further three feedback questions. Census questions related to clinic/service setting/location, staff, patient demographics, referrals, clinical investigations, and research engagement. Census questions could broadly be categorised into the following topics: geography, service type, staff demographics, patient demographics, referral criteria, clinical investigations, and research engagement. A full list of questions and respective response options for the Scottish Cognitive Clinics Census (2021) is provided in the Appendix.

3.3. Findings

3.3.1. Response Rates

We received responses from 57 clinics. 53 of these were eligible and accurate, and 43 of those completed the entire census (with 10 completing the eligibility page only). Results presented here were derived from the 43 completed responses. A flow-chart of the data cleaning process is provided in Figure 2.

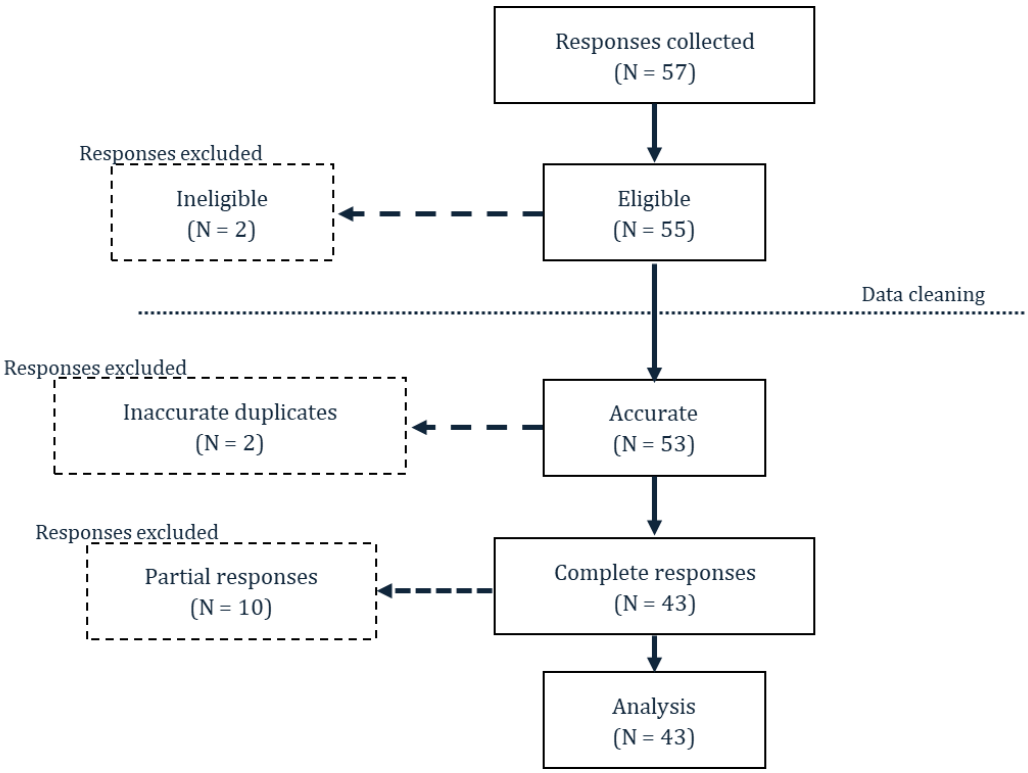

Figure 2. Flow chart for census data cleaning process.

3.3.2. Clinic Demographics

i. Health Boards and Local Authorities

Within the final 43 responses analysed, we received at least one complete response from each health board (100% reach) and at least one complete response from 28 out of 32 local authorities (87.5% reach). The maximum number of responses per health board was 8, and for local authorities was 6. Figure 3 shows number of responses per health board, and Figure 4 shows responses per local authority.

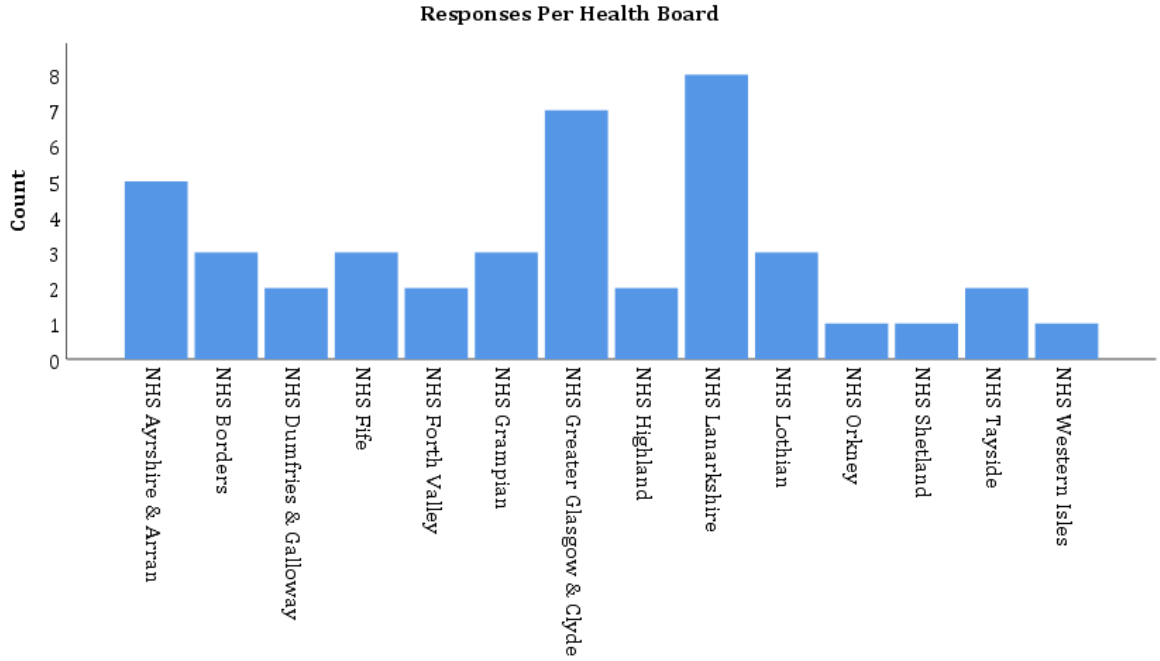

Figure 3. Number of valid census responses per health board.

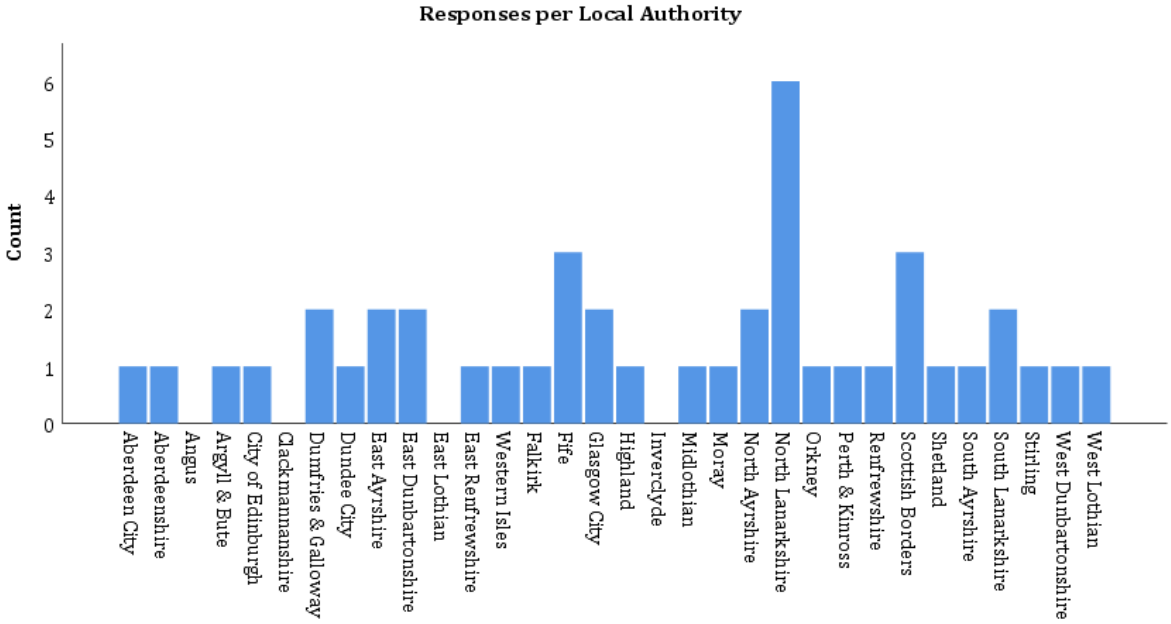

Figure 4. Number of valid census responses per local authority.

ii. Service type and clinic setting

Most services described themselves as Community Mental Health Teams (48.8%), Memory Clinics/Cognitive Clinics/Dementia Services (18.6%), or Psychiatry Outpatient Clinics (16.3%). Other service types included. Post-diagnostic support clinics made up 4.7% of responses. The following service types, including those responding 'other' providing self-definitions, each comprised 2.3% of the total respondents: Neurology Outpatient Clinic, Young Onset Clinic, Delirium Call-Back Clinic, Research Clinic, and combined CMHT/Psychiatry Outpatient Clinic. 0% of responding services described themselves as inpatient assessment services. Service type proportions are shown in Figure 5.

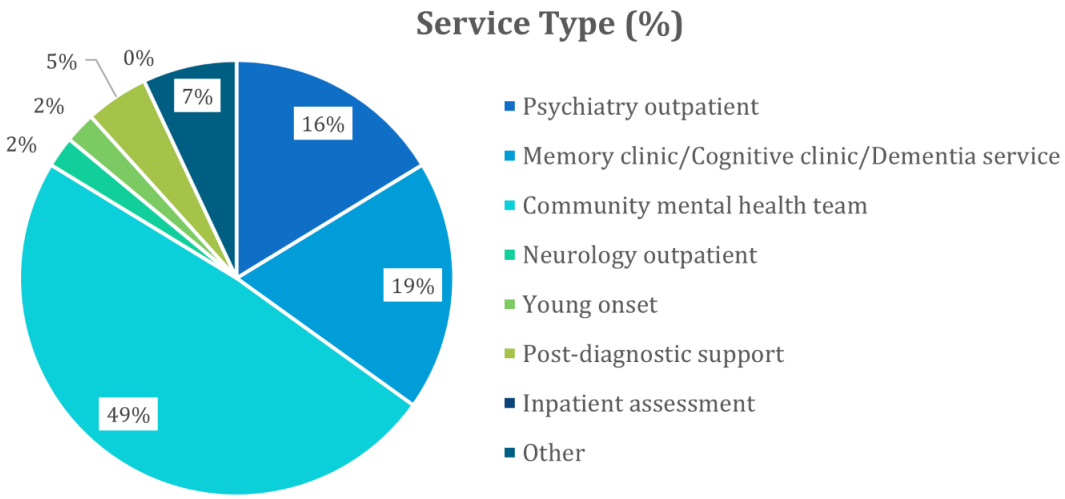

Figure 5. Proportions of service types.

Services were provided most often in designated clinic settings (46%), domestic/home-visit settings (33%). 7% of respondents provided services in various clinical settings (e.g., GP surgeries, health centres). 14% of respondents provided services across a combination of clinic and domestic settings. Figure 6 shows proportions of clinic settings.

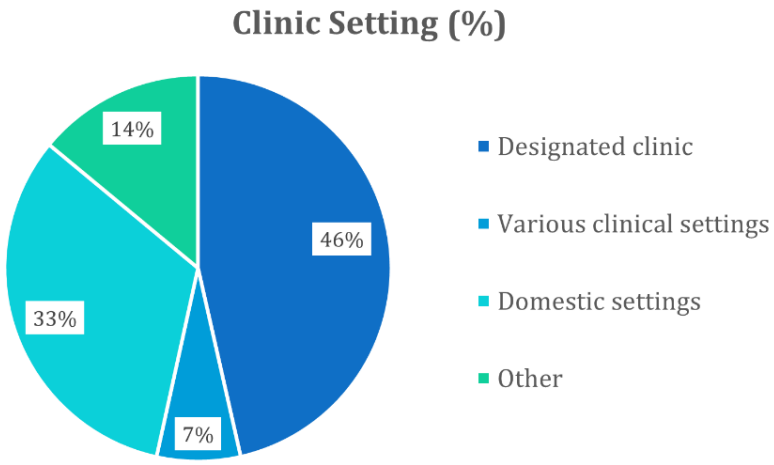

Figure 6. Proportions of clinic settings.

Staff Types

Responding services most commonly had Psychiatrists (93%), Nurses (81.4%), Occupational Therapists (60.5%), and Clinical Psychologists (44.3%) on staff. A full breakdown of staff types in shown in Figure 7. 'Other' staff types included healthcare support workers, post-diagnostic support workers, social workers, clinical nurse specialists, and dementia link workers.

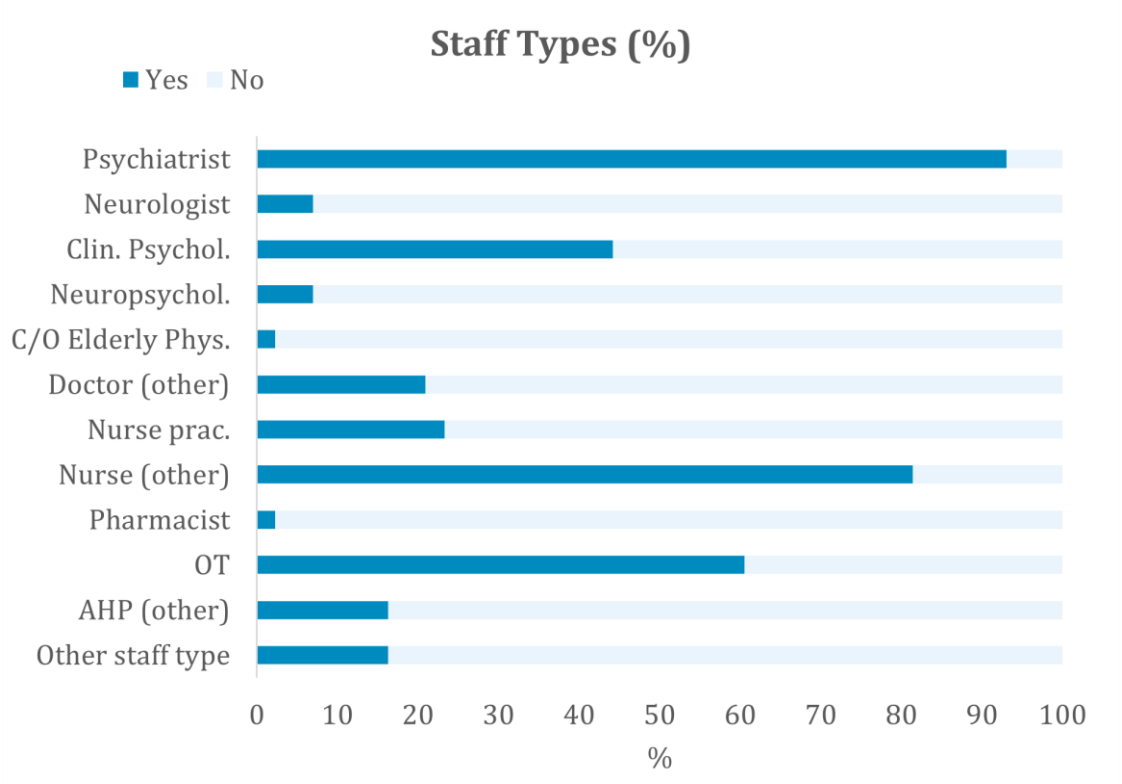

Figure 7. Proportion of staff types.
Note. OT: Occupational Therapist, AHP: Allied Health Professionals.

Nurses most commonly conduct the patient's initial assessment (58% of services), with a Multidisciplinary-team-led initial assessment and a doctor-led initial assessment each occurring in 21% of services. Figure 8 shows the proportions of initial assessor staff types.

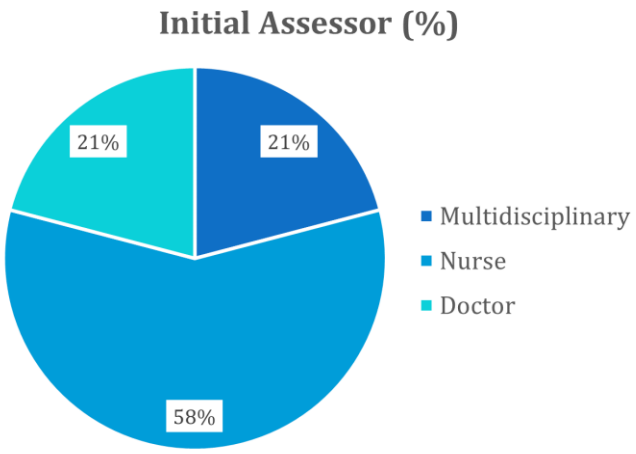

Figure 8. Proportion of initial assessor staff types.

Patient Demographics

i. Patient age

The most common patient age-group was 75 to 84 years (72% of services), followed by 65 to 74 years (24% of services). 2% of services reported the most common age-group of patients was over 85 years, and 2% reported the most common age-group as 55 to 64 years. No services reported the 35 to 44 or the 45 to 54 age groups to be the most common. Age-group proportions are shown in Figure 9.

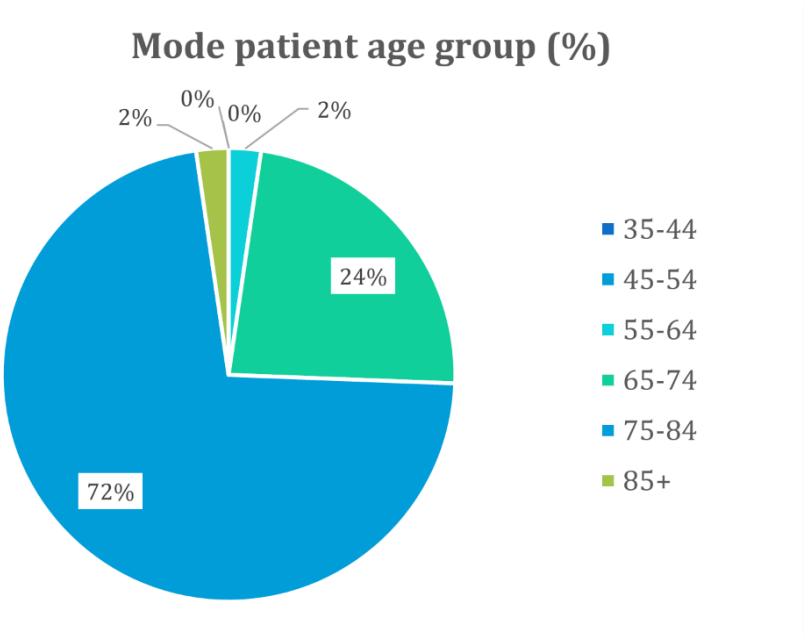

Figure 9. Proportions of most common (mode) patient age group.

ii. Common diagnoses

The diagnoses most frequently described as 'very common' in these services was Alzheimer's Disease (62.8% of services), followed by Vascular Dementia (53.5%), and Mixed Dementias (51.2% of services). Dementia with Lewy Bodies and Mild Cognitive Impairment were most often described as 'common' diagnoses (46.5% and 44.2% of services, respectively). Frontotemporal dementia and Secondary dementias were more often described as 'uncommon' diagnoses in responding services (50% and 46.5% of services, respectively). Functional Cognitive Disorder was described as a 'very uncommon' diagnosis in 31.7% of services. Distributions of diagnostic frequencies are presented in Table 7.

Table 7. Frequencies for commonness of diagnoses ratings

Diagnosis	Ratings for commonality of diagnoses (%)				
	Rare/ Never	Very uncommon	Uncommon	Common	Very common
Alzheimer's disease	0	0	4.7	32.6	62.8
Mild cognitive impairment	0	0	18.6	44.2	37.2
Secondary dementia	2.3	11.6	46.5	39.5	0
Vascular dementia	0	0	7	39.5	53.5
Frontotemporal dementia	0	23.8	50	26.2	0
Mixed dementia	0	0	9.5	38.1	52.4
Dementia with Lewy Bodies	2.3	14	34.9	46.5	2.3
Functional Cognitive Disorders	24.4	31.7	26.8	14.6	2.3

iii. Patient demographics routinely collected

The majority of services collect basic demographic information, including patient age (97.5%), address (95.3%), sex (86%), next of kin (86%), and marital status (81.4%). Fewer services collect demographic information relating to protected characteristics such as religion (30.2%), sexual orientation (11.6%), and gender reassignment (9.3%). Approximately half of responding services collected demographic information about factors which may affect performance on standard cognitive testing, including patient's first language (51.2%) and disability/accessibility requirements (55.8%). Proportion of services routinely collecting various demographic data are shown in Figure 10.

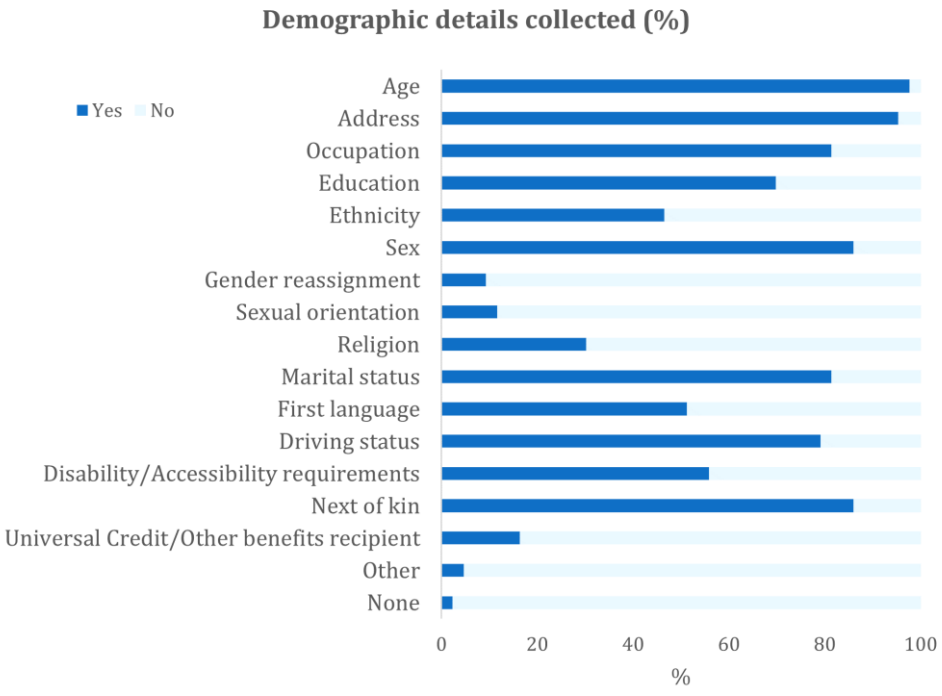

Figure 10. Proportion of services routinely collecting various types of demographic data.

iv. Patients receiving cognitive enhancer medications

The median proportion of patients receiving 'cognitive enhancer' medications (such as donepezil) was 60%. Responses ranged from 0% to 97%. 7% of services reported that below 25% of patients receive cognitive enhancer medications, and 25.6% of services reported that over 75% of patients received these medications. Figure 11 shows the distribution of approximate percentage of patients receiving cognitive enhancer medications.

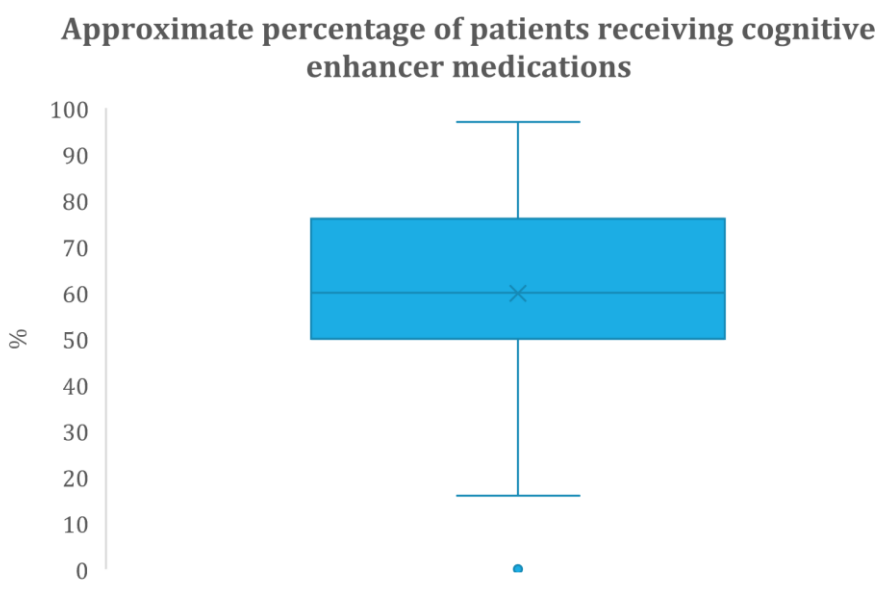

Figure 11. Approximate percentage of patients receiving cognitive enhancer medications.

Referral Process

i. Waiting time

A quarter of services make a first appointment with patients within four weeks of referral (25.6%). In 35% of services, patients are seen within eight weeks of referral, and a further 30.2% are seen within twelve weeks – or three months – of referral. Waiting time proportions are shown in Figure 12.

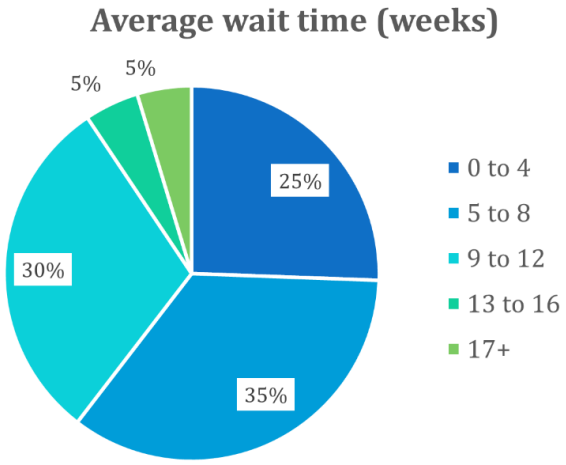

Figure 12. Proportion of average waiting times from referral to first assessment (weeks).

ii. Annual referrals

Most services receive between 51 to 200 referrals per year. 39% of services receive over 201 referrals per year. 7% of services receive 50 or fewer referrals per year. Proportions of average annual referrals received are shown in Figure 13.

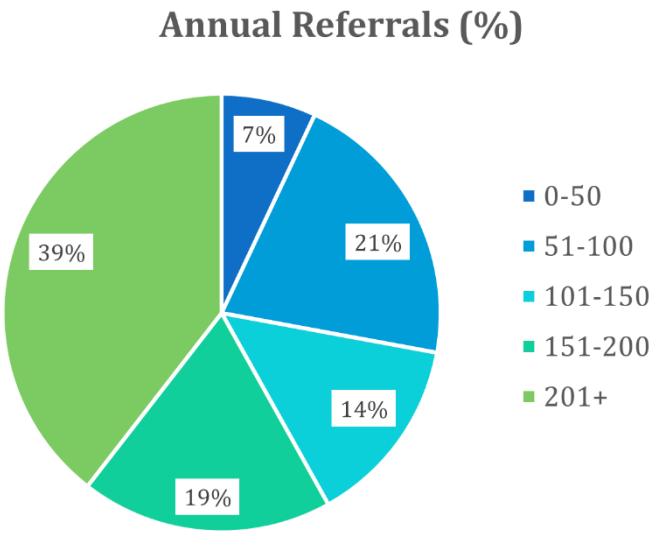

Figure 13. Proportions of average annual referrals received.

iii. Referral criteria

The most commonly required referral criterion was a prior blood test (51.2% of services), followed by a lower age limit (e.g., service for patients over 65 years; 44.2% of services). A cognitive test score was required in 41.9% of services. Proportions of various referral criteria required are presented in Figure 14.

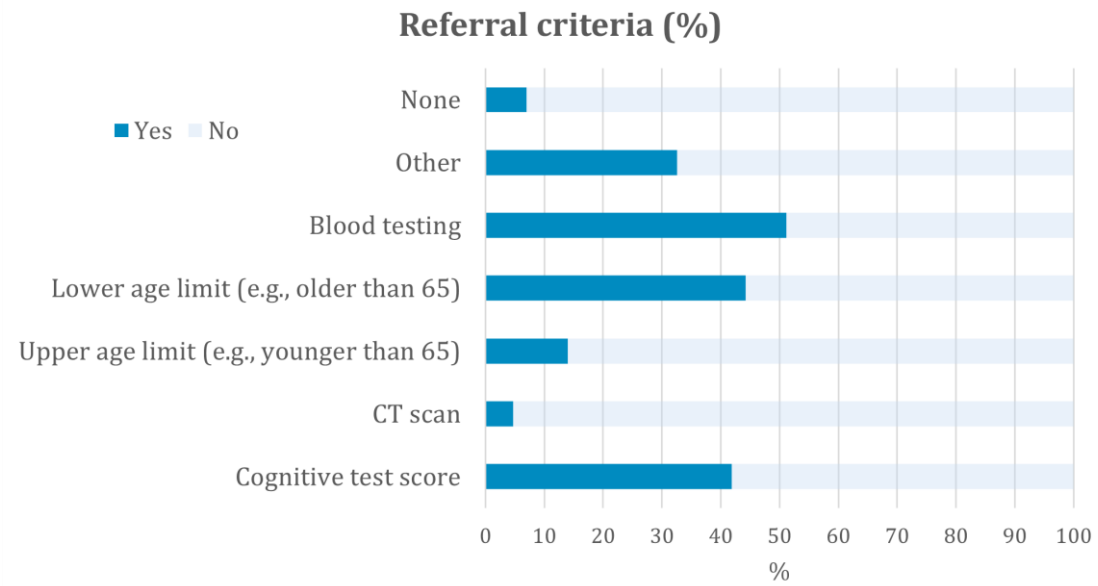

Figure 14. Proportions of services requiring various referral criteria.

Clinical Investigations

The most commonly used cognitive assessments were the Addenbrooke's Cognitive Examination (97.7%), the Montreal Cognitive Assessment (46.5%), and the Mini Mental State Examination (39.5%). Proportions of cognitive tests administered are shown in Figure 15.

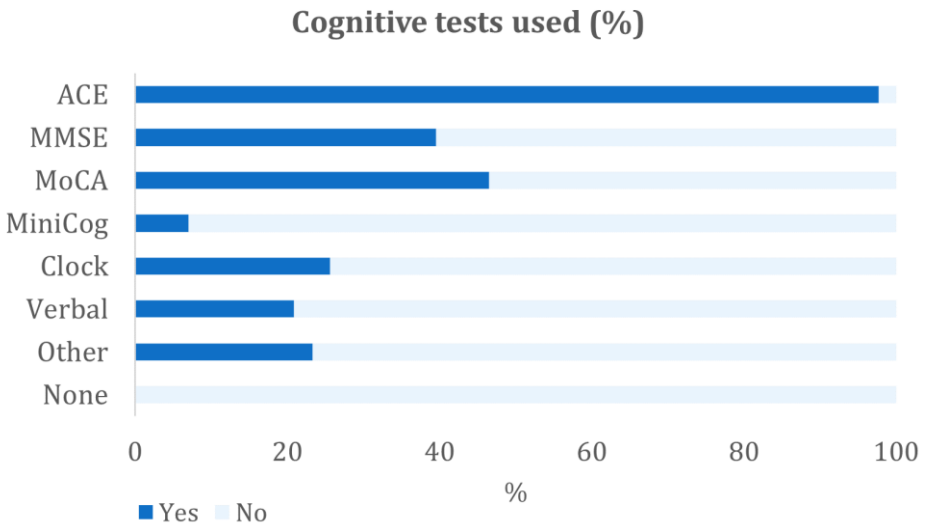

Figure 15. Percentage of services administering assorted cognitive examinations.
Note. ACE: Addenbrooke's Cognitive Examination; MMSE: Mini Mental State Examination; MoCA: Montreal Cognitive Assessment.

The median approximate percentage of patients undergoing cognitive testing in responding services was 96% (minimum: 8%, maximum: 100%). Median (minimum - maximum) approximate percentages for referring patients for brain imaging was 70% (10-100%), for CSF testing was 0% (0-25%), and for genetic testing was 1% (0% to 50%). Figures 16 to 19 show distribution of approximate percentage of patients undergoing or referred for each modality of clinical investigation.

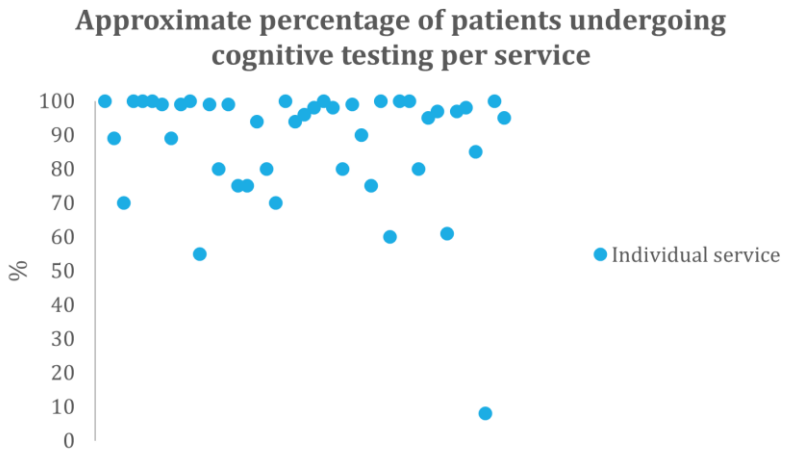

Figure 16. Distribution of approximate percentage of patients undergoing cognitive testing per service.

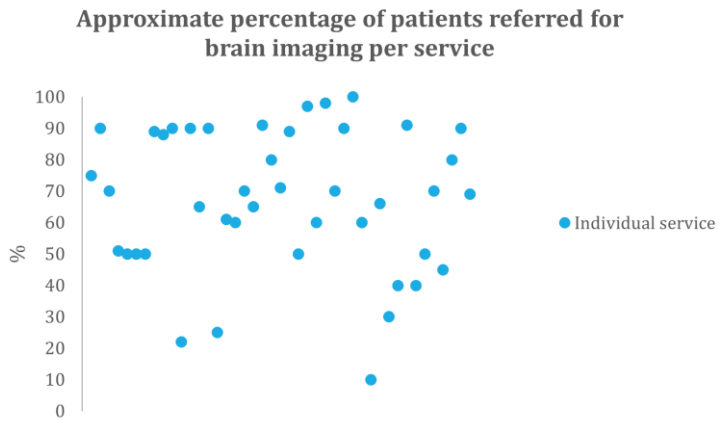

Figure 17. Distribution of approximate percentage of patients referred for brain imaging per service.

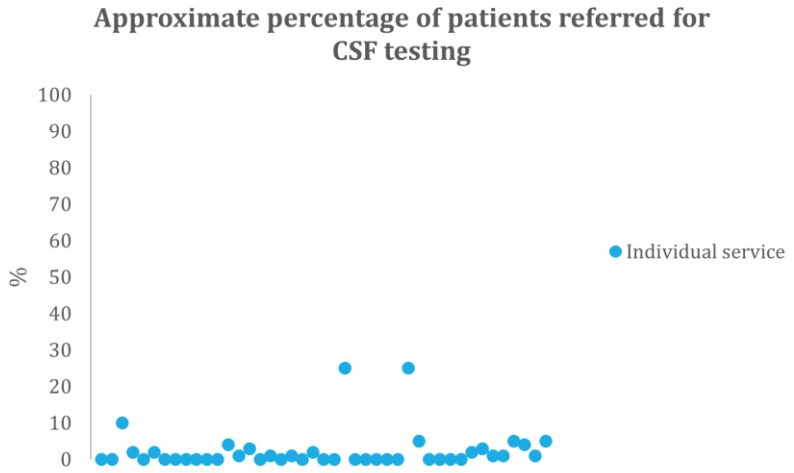

Figure 18. Distribution of approximate percentage of patients referred for cerebrospinal fluid (CSF) testing per service.

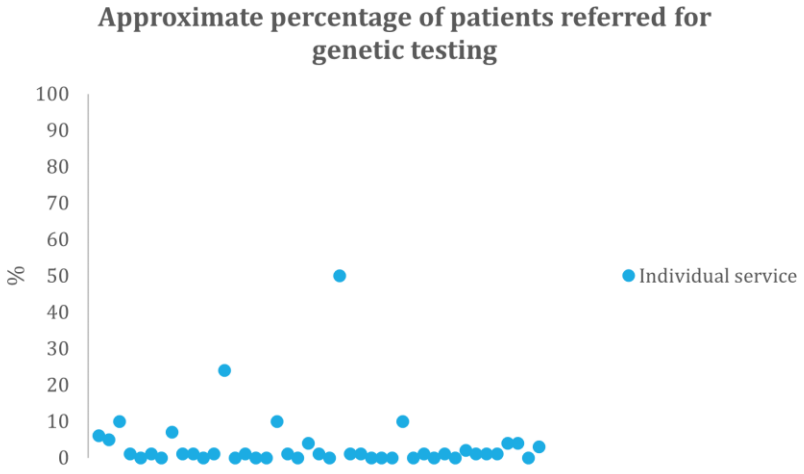

Figure 19. Distribution of approximate percentage of patients referred for genetic testing per service.

Research Activity

Most services reported some form of involvement in research activity (81.4%). Types of research activity reported included supporting patient enrolment in clinical trials (37.2%), encouraging patients to register with the Join Dementia Research platform (39.5%), having a clinical academic or researcher on staff (14%), encouraging the clinic to engage in research activities (11.6%), encouraging clinic staff to engage in research activities (23.3%), or another form of research activity (4.7%). Proportions of services engaging in various research activities are presented in Figure 20.

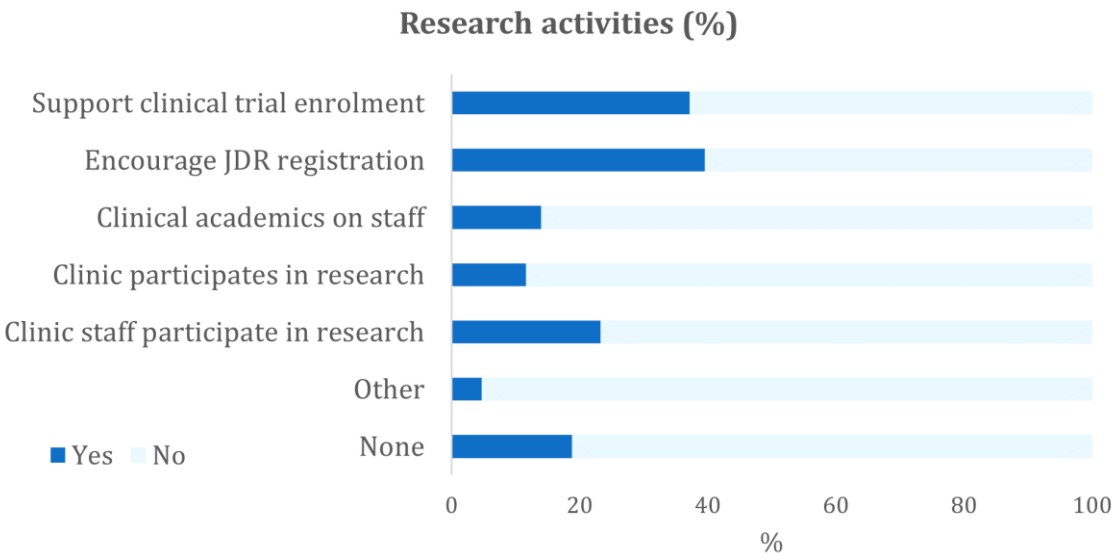

Figure 20. Proportions of research activities undertaken.

4. Concluding Remarks

The present scoping exercise aimed to collate publicly available information and produce novel data relating to the clinical assessment of cognitive complaints in Scotland. The scoping exercise comprised of two main stages: an evaluation of information publicly available through health board websites and FOI requests, and delivery of a census of Scotland's cognitive clinics.

We provided an overview of the academic and 'grey' literature relating to the clinical assessment of cognitive complaints internationally and in the wider UK and Scotland. We then evaluated fourteen health board websites, finding a small number of examples of good practice. Typically, websites were difficult to navigate, and information provided was largely generic. We sent FOI requests to all fourteen health boards, with twelve providing information about the type and location of their cognitive clinics, one health board reporting their region provides assessment of cognitive complaints but without providing location information, and one health board reported they had no relevant services in their area. We created a map of clinics and team hubs where locations were provided. From the FOI responses, we determined there were approximately 58 services for assessing cognitive complaints in Scotland. Finally, we conducted the Scottish Cognitive Clinics Census (2021), in which clinics provided descriptive demographic information relating to their service location, staffing, patients, referral criteria, clinical investigations, and research engagement. We received a high response rate (43 valid responses), and were able to provide valuable descriptive insights into each of the topics covered by the census. While we did not conduct inferential statistics, it was apparent that there were differences in clinical service provision across Scotland.

In summary, across all areas of our information gathering, we found that there did not appear to be a standardised approach to the assessment of cognitive complaints in services across Scotland. Services in different regions appear to thrive in different areas of their service provision, and there appears to be a lack of uniformity in the implementation of the assessment and care pathway.

This scoping exercise was an initial step in creating a repository of benchmarking information on clinical service provision for assessing cognitive complaint in Scotland. While it is outwith the scope of the current report to provide recommendations on the provision of clinical services, we do recommend that similar scoping exercises are conducted longitudinally (over time). Continuation of this scoping exercise process in future years will enable identification of trends in service provision and enable monitoring of service-level responses to changes in policy or practice. This will be of increasing importance as a greater proportion of the population require assessment for cognitive complaints, and as early disease detection methods improve, and disease-modifying therapies become approved for use in Scotland.

Appendix

Scottish Cognitive Clinics Census (2021): Census questions and response options

July 2021, v2

Introduction

Thank you for your interest in the Scottish Cognitive Clinics Census (2021). This census is being conducted by Brain Health Scotland in collaboration with Alzheimer Scotland, with funding from the Chief Scientist Office and Biogen. The census aims to gather information on current clinical services for people with cognitive concerns in Scotland.

Census Guidance

The census is made up of 20 questions, and **should take 10 minutes** to complete.
There are 3 screening questions prior and 3 debriefing questions following the census. 26 questions in total, 10-15 minutes to complete the lot. An ideal opportunity for a cup of tea.

We only require **one response per clinic/service**, so please choose the person best suited to fill this out.

We don't want you to spend any time looking up information, so please just **give us your best guesses.**

Finally, we appreciate that things have been a little different lately, which makes us all the more grateful for your time. **Please answer as though it were a typical year** (free from COVID-19 restrictions).
It may help to answer these questions as you would have in 2019.

Thank you again for your participation!
If you have any questions or comments, please contact the census coordinator (Dr. Jenny Waymont: jwaymont@alzscot.org).

We'll begin with a few eligibility questions before we move onto the census.

Eligibility

Question	Response type	Response options
Is the clinic/service located in Scotland?	Multiple choice	Yes / No
Please provide the postcode of the clinic/service. For those providing care in various locations, please provide the postcode of your team base. N.B. The postcode is required to check for duplicate responses and to explore rural/urban access to clinics. It will not be used to identify the clinic/service in our reporting.	Free text	
Does the clinic/service provide clinical assessment of individuals with cognitive concerns? (E.g., dementia, mild cognitive impairment).	Multiple choice	Yes / No

Census

Question	Response type	Response options
1. In which health board is the clinic/service located?	Drop-down list	NHS Ayrshire and Arran / NHS Borders / NHS Dumfries and Galloway / NHS Fife / NHS Forth Valley / NHS Grampian / NHS Greater Glasgow and Clyde / NHS Highland / NHS Lanarkshire / NHS Lothian / NHS Orkney / NHS Shetland / NHS Tayside / NHS Western Isles
2. In which local authority is the clinic/service located?	Drop-down list	Aberdeen City / Aberdeenshire / Angus / Argyll and Bute / City of Edinburgh / Clackmannanshire / Dumfries and Galloway / Dundee City / East Ayrshire / East Dunbartonshire / East Lothian / East Renfrewshire / Western Isles / Falkirk / Fife / Glasgow City / Highland / Inverclyde / Midlothian / Moray / North Ayrshire / North Lanarkshire / Orkney / Perth and Kinross / Renfrewshire / Scottish Borders / Shetland / South Ayrshire / South Lanarkshire / Stirling / West Dunbartonshire / West Lothian
3. Which of the following best describes the clinic/service?	Multiple choice (single selection)	Psychiatry outpatient clinic / Memory clinic/Cognitive clinic/Dementia services / Community Mental Health Team / Neurology outpatient clinic / Young onset clinic / Post-diagnostic support clinic / Inpatient assessment (e.g., psychiatry, neurology, acute) / Other (please specify)
4. Where does the clinic/service mainly conduct assessments?	Multiple choice (single selection)	In a designated/permanent clinical setting (i.e., patients come to the clinic) / In various clinical settings (e.g., GP practices, health villages) / In the patient's home (including sheltered accommodation) / Inpatient setting (hospital wards, long-term care facilities, hospice) / Other (please specify)
5. What, if any, are the criteria for accepting a referral? (Select all that apply)	Checkboxes (multiple selections)	Cognitive test threshold (e.g., MMSE score) / CT scan prior to referral (e.g., GP requested) / Age threshold – upper limit (e.g., younger than 65 for young onset clinic) / Age threshold – lower limit (e.g., age 65 or above) / Blood testing prior to referral (e.g., GP requested) / Other (please specify) / None of the above

Question	Response type	Response options
6. Approximately how many referrals does the clinic receive in a typical year?	Multiple choice (single selection)	0 – 50 / 51 – 100 / 101 – 150 / 151 – 200 / 201+
7. Approximately how many weeks is the average waiting time from referral to first appointment in a typical year?	Multiple choice (single selection)	0 – 4 weeks / 5 – 8 weeks / 9 – 12 weeks / 13 – 16 weeks / 17+ weeks
8. Which age group do the majority of patients belong to?	Multiple choice (single selection)	35 – 44 years / 45 – 54 years / 55 – 64 years / 65 – 74 years / 75 – 84 years / 85+ years
9. Which, if any, of the following patient demographics are routinely collected? (Select all that apply)	Checkboxes (multiple selections)	Age / Address / Occupation / Education / Ethnicity / Sex / Gender reassignment / Sexual orientation / Religion / Marital status / First language / Driving status / Disability status/Accessibility requirements / Next of kin / Universal credit/Other benefits recipient / Other (please specify) / None of the above
10. Which of the following types of staff regularly work in the clinic/service? (Select all that apply)	Checkboxes (multiple selections)	Psychiatrist / Neurologist / Clinical Psychologist / Neuropsychologist / Care of the Elderly Physician / Doctor (other) / Nurse practitioner / Nurse (other) / Pharmacist / Occupational therapist / Allied Health Professional (other) / Other (please specify)
11. Who conducts the initial assessment(s)?	Multiple choice (single selection)	Multidisciplinary / Nurse / Doctor
12. How is cognition assessed? (Select all that apply)	Checkboxes (multiple selections)	Addenbrooke's Cognitive Exam (e.g., ACE-III, ACE-R, m-ACE) / Mini Mental State Exam (MMSE) / Montreal Cognitive Assessment (MoCA) / Mini-Cog / Clock-drawing test / Verbal fluency test / Other (please specify) / None of the above
13. Approximately what proportion of patients undergo cognitive testing?	Slider	0 – 100%
14. Approximately what proportion of patients are referred for brain imaging?	Slider	0 – 100%

Question	Response type	Response options
15. Approximately what proportion of patients are referred for CSF (cerebrospinal fluid) testing? (i.e., lumbar puncture)	Slider	0 – 100%
16. Approximately what proportion of patients are referred for genetic testing?	Slider	0 – 100%
17. Approximately what proportion of patients are prescribed 'cognitive enhancer' medications? (e.g., Donepezil, Memantine)	Slider	0 – 100%
18. Please indicate how commonly or uncommonly each of the following conditions are diagnosed in the clinic/service	Likert scale: Very common / Common / Uncommon / Very uncommon / Rare/never	Alzheimer's disease / Mild cognitive Impairment / Secondary dementia (e.g., relating to Parkinson's disease, HIV, Huntington's disease, etc.) / Vascular dementia / Frontotemporal dementia / Mixed dementia / Dementia with Lewy Bodies / Functional Cognitive Disorder
19. How does the clinic/service promote research participation? (Select all that apply)	Checkboxes (multiple selections)	Support enrolment in clinical trials / Encourage Join Dementia Research (JDR) registration / Academic clinicians on staff / Clinic/service participates in research activities / Clinic staff encouraged to participate in research activities / Other (please specify) / None of the above
20. Please use this space to share some examples of best practice or challenges faced by the clinic/service, or tell us anything else you'd like us to know about the clinic/service.	Free text	

Debrief

Thank you for taking the time to complete the 2021 Scottish Cognitive Clinics Census!

If you would like to receive a report on how the clinic/service you have answered about today compares with other clinics/services in Scotland, please complete the contact information requested below. We will contact you with a confidential unique identifier code for your clinic/service, which will enable you to identify your own clinic/service in comparison with others, while keeping all responding clinics/services anonymous.

Any comments or questions about receiving a report or about any broader aspect of the Scottish Cognitive Clinics Census 2021 can be directed to Brain Health Scotland's research officer, Dr. Jenny Waymont (jwaymont@alzscot.org).

Question	Response type	Response options
i. Please provide contact information if you wish to receive a Unique Identifier Code for a personalised comparative report	Text	Name, health board, email address
ii. Would you be happy for Brain Health Scotland to contact you regarding further quality improvement activities? We will only contact you if relevant opportunities arise. We will not use your contact information to identify you or your clinic/service. If you select 'no', we will use your contact information only to provide a unique identifier code and comparative report and will delete your contact information when this has been supplied.	Multiple choice (single selection)	Yes / No
iii. Finally, would you complete the Scottish Cognitive Clinics Census again in future?	Multiple choice (single selection)	Yes / No / Maybe

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