Brain Health Services:
Recommendations for Clinical Practice

Alzheimer Scotland
Action on Dementia

Brain Health Scotland

Our mission is to empower everyone in Scotland to protect their brain health and reduce their risk of diseases that lead to dementia.

Brain Health Scotland Strategy 2022

Cite this document as:
Brain Health Scotland (2023) Brain Health Services: Recommendations for Clinical Practice.

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Foreword by the Chief Executive of Alzheimer Scotland

In 2018 myself and Professor Craig Ritchie met with the then First Minister Nicola Sturgeon to discuss the new and emerging possibilities of dementia prevention. This was the start of an exciting and innovative new movement towards the development of Brain Health Scotland and dementia prevention in Scotland.

Soon after this meeting the concept and vision of Brain Health Scotland was born. With core funding from the Scottish Government combined with contributions from Alzheimer Scotland the journey to transform and build this new approach commenced. Brain Health Scotland was formally launched in April 2020. Our goal is to promote lifelong brain health and long-term dementia prevention strategies. By reaching out as early as possible into our schools and broader community we can actively engage with the general public and target people known to be at risk of brain disorders.

We have focused on the development of brain health promotion and personalised risk reduction plans. We have also collaborated with researchers and the NHS to increase the number of people engaged in research in Scotland, particularly people from less advantaged communities. We aim to position Scotland as a leader in the field of brain health development and research. Perhaps the most ambitious component of this vision is the development of Brain Health Clinics.

It is quite remarkable to think that we set out to do all of this at the height of the COVID-19 pandemic, which devastated our dementia community and stretched our health and social care services beyond anything anyone thought possible. Yet, despite this, our team and our partners kept moving forward, embracing innovations and opportunities that arose despite the pandemic.

The model for Brain Health Services and Clinics described in these recommendations has been developed in partnership with clinical colleagues in public health, neurology, psychiatry, nursing, and allied health care professionals. These are not definitive national clinical recommendations, but a model that we believe can deliver what we know is possible in terms of dementia prevention and one that is well placed to maximise the new treatment and diagnostic measures we know are coming to fruition.

Alongside this, we have embarked on a transformation, taking dementia further out of the shadows and cloak of discrimination it has been shrouded in by shifting the paradigm towards a greater understanding that many forms of dementia are preventable. If we see dementia through the lens of brain health everything changes and possibilities emerge that we have been missing. This is why we have been transitioning our centres throughout Scotland to Brain Health and Dementia Resource Centres. To see the first Brain Health Clinic in Scotland hosted in our centre in Aberdeen is one of the most positive developments that we have ever been a partner in. We are deeply grateful to NHS Grampian and Public Health for walking down this new path with us and for the Scottish Government for their funding, support, and commitment towards this new vision.

Now a new journey begins, can we make it work. We recognise the level of rigour and detailed evaluation that will be required to grow this movement and replicate this model. That is how it should be. I am confident that this new model and the approaches outlined in these recommendations provide a solid foundation for moving forward and that together we can ensure that Scotland leads the way in Brain Health Clinics throughout the world.

Henry Simmons
Chief Executive
Alzheimer Scotland

Foreword by the Clinical Advisor of Brain Health Scotland

As a neurologist specialising in dementia and other memory and thinking disorders, it has been a huge privilege to work with Brain Health Scotland and NHS Grampian colleagues to develop these recommendations for clinical practice. This is a very exciting time for everyone working on memory and thinking disorders. There is increasing evidence that many cases of dementia can be prevented. We have real hope of novel agents for the treatment of Alzheimer's disease being licensed in the very near future, and biomarkers for Alzheimer's disease are progressively becoming more accessible. Successfully embedding Brain Health Clinics into our health care system is key to ensure that brain health messages are widely disseminated to the general public, and that people have easy access to practical, personalised support in managing their dementia risk factors. When novel therapies are licenced for mild cognitive impairment and early-stage dementia, Brain Health Clinics will be ideally placed to support early, accurate identification of neurodegeneration.

This model is a first iteration, and it will be regularly updated as scientific knowledge and the therapeutic landscape evolves.
The model is intended to be practical and pragmatic, and we know that local modifications will be needed to suit specific population needs. We hope that NHS colleagues will find the model useful, and I look forward to seeing how it performs in our first Brain Health Clinic in NHS Grampian.

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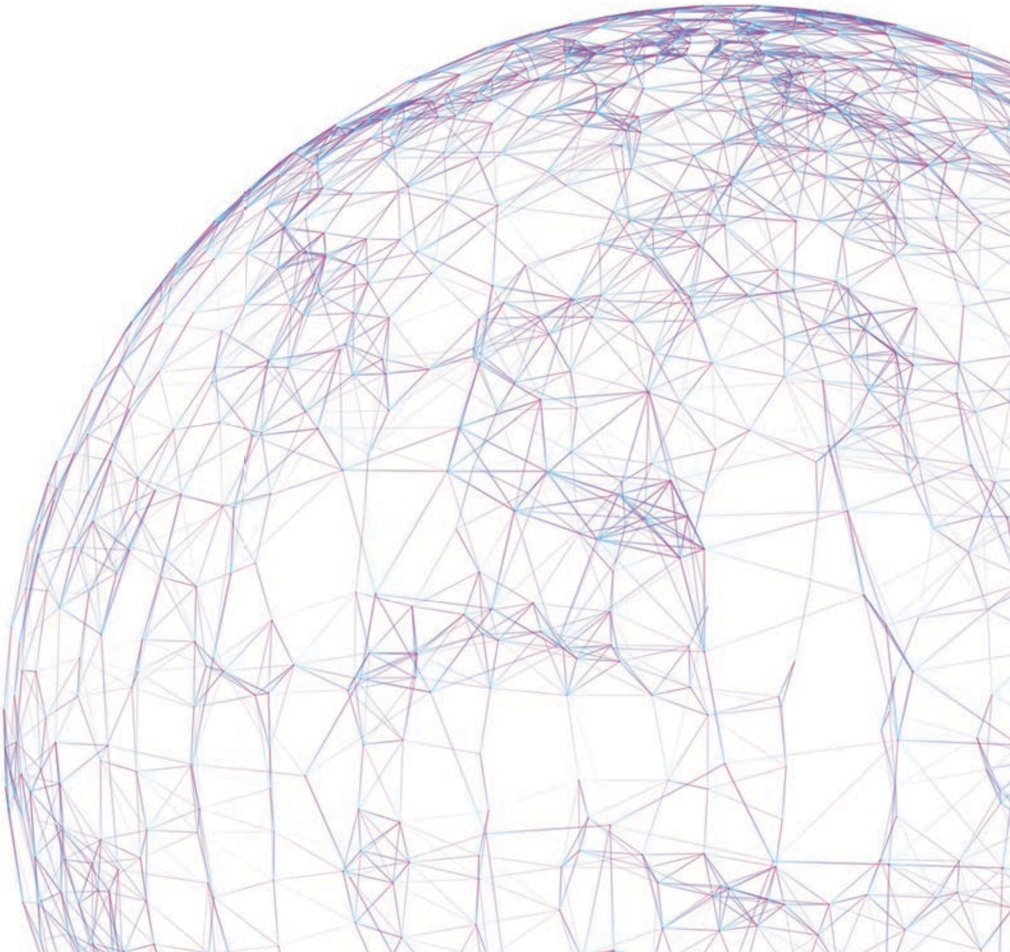

Development of the Recommendations

These guidelines build on recommendations in the Scottish Model for Brain Health [1], adapted for current NHS clinical practice. In adopting recommendations and following instructions provided here, we enable a uniform approach to brain health service provision across Scotland.

Where clinical uncertainty exists, practitioners should refer to relevant NICE and SIGN guidelines, along with local protocols and their own clinical judgements.

Brain health services are a rapidly evolving area of clinical practice, and we anticipate that these recommendations for clinical practice will evolve in response to emerging evidence and clinical practice experience. The recommendations are written at a national level, and appropriate localisation of onward referral pathways (e.g., signposting to local support services, such as local smoking cessation services) and consideration of specific local population needs (e.g., rural areas, areas with larger populations with English as a second language, areas of high socioeconomic disadvantage) is recommended.

The model presented in these recommendations is based on partnership working between Alzheimer Scotland and local NHS Scotland health boards. Modified approaches can be applied in other settings across the United Kingdom and wider afield.

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[1] Ritchie, C.W., Waymont, J.M., Pennington, C., Draper, K., Borthwick, A., Fullerton, N., Chantler, M., Porteous, M.E., Danso, S.O., Green, A. and McWhirter, L., (2022). The Scottish Brain Health Service Model: Rationale and Scientific Basis for a National Care Pathway of Brain Health Services in Scotland. *The Journal of Prevention of Alzheimer's Disease*, Vol 2(9) pp.348-358

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This version of the recommendations for clinical practice was shared with colleagues in NHS Grampian for feedback, as hosts of the first brain health service demonstrator site. We anticipate future iterations of brain health service recommendations for clinical practice will incorporate feedback from further demonstrator sites and, ultimately, from brain health services across Scotland.

Disclosures

CP has previously received honoraria from GE Healthcare. She has funded academic time (separate from Brain Health Scotland/ Alzheimer Scotland) arising from a Chief Scientist Office NRS Career Researcher Fellowship.

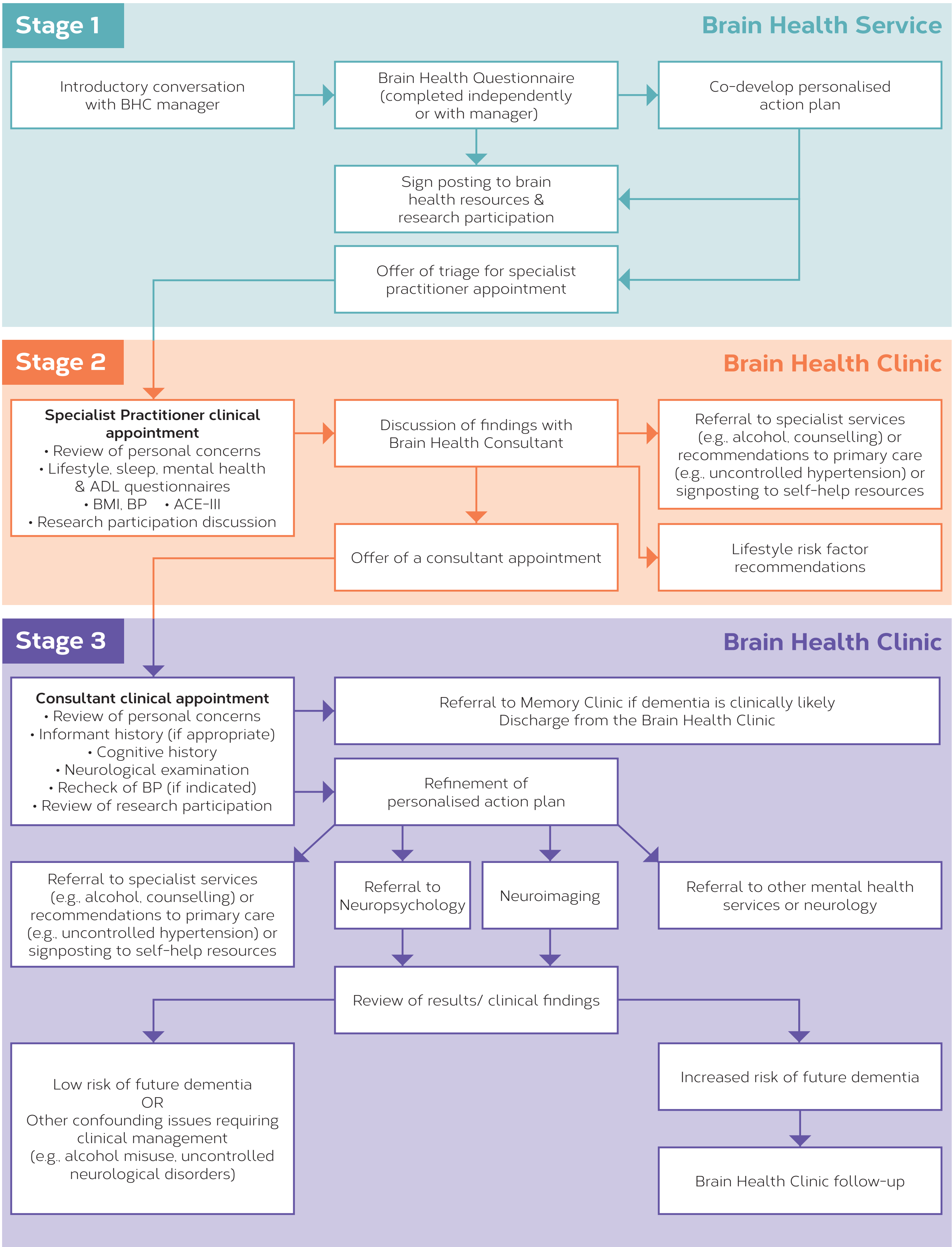
JW received consultancy funding for work supporting the development of the recommendations for clinical practice (03.2023-06.2023), and salary funding for a prior scoping exercise of Scottish cognitive clinics (2020-2022) from an education grant from Biogen provided to BHS/AS. JW currently receives academic funding (separate from work for BHS) from the UK Dementia Research Institute (Edinburgh), the Weston Brain Institute, and from Dementias Platform UK (MRC) (2022-2024).

HS, HM, EH, NF, and AB have no funding or conflicts of interest to declare.

Glossary

Terminology/Abbreviation/Acronym	Definition
ACE-III	Addenbrooke's Cognitive Examination (Version 3)
AD	Alzheimer's disease
ADD	Alzheimer's disease dementia
ADL	Activities of Daily Living
Alzheimer Scotland Brain Health and Dementia Resource Centre	The Alzheimer Scotland premises, housing the brain health clinic and providing brain health information. Referred to in guidance as 'the centre' for brevity.
BHC	Brain health clinic
Alzheimer Scotland Centre Manager	A (non-clinical) member of Alzheimer Scotland staff, working in brain health service to provide information about brain health and the brain health care pathway. Referred to in guidance as 'the centre manager' for brevity.
BHS/AS	Brain Health Scotland / Alzheimer Scotland
CNS	Central nervous system
CSF	Cerebrospinal fluid
CT	Computerised Tomography (imaging modality)
GP	General Practitioner
HMPAO SPECT	Hexamethylpropyleneamine Oxime Single Photon Emission Computer Tomography
MCI	Mild Cognitive Impairment
MRI	Magnetic Resonance Imaging (imaging modality)
Patient	An individual referred to the brain health clinic
Person (or individual)	A person attending an Alzheimer Scotland service who is not yet referred to the brain health clinic (i.e., all people attending prior to becoming a 'patient' under NHS care). Referred to in the guidance interchangeably as 'the person', 'people', 'persons', 'the individual', 'individuals'.
PET	Positron Emission Tomography
Practitioner	NHS clinical staff working within the brain health clinic, and allied health professionals working within the Alzheimer Scotland Centre
SCD	Subjective Cognitive Decline

Brain Health Care Pathway Flowchart



1

Stage 1: Brain Health Service

1.1. Stage 1 Overview

The Alzheimer Scotland Brain Health and Dementia Resource Centre is set up to provide publicly accessible resources on the topic of brain health. The centre holds information resources about assessing, maintaining, and improving brain health. The centre is staffed by an Alzheimer Scotland Centre Manager employed by Alzheimer Scotland. The centre manager is available to assist members of the public accessing the centre resources and help them work through non-clinical brain health assessments and take referrals to the Brain Health Clinic. Members of the public have direct access to the centre during working hours, and are free to browse resources, work though brain health assessments and discuss queries with the centre manager, as they wish.

1.1.1. First Contact

The first point of contact with the brain health pathway for members of the public is with the centre manager.

The centre manager does not require to be clinically trained. The centre manager will be trained in different potential individual scenarios (see document 'Clinical Vignettes' for examples; Appendix A) and in assessing brain health risk factors.

The centre manager will introduce the service to the individual and offer to work through the Brain Health Questionnaire with them (see Section 1.1.3 and Appendix B) and the demographics proforma (Appendix C).

1.1.2. People who do not wish to discuss information with the manager

Some people will prefer to work through the Brain Health Questionnaire (Appendix B) independently and/or not, to discuss their risk factors with the centre manager.

The centre manager will signpost to the Brain Health Questionnaire and to the Brain Health Scotland website (specifically the 'My Brain Health' quiz) and advise that the person is free to browse the resources and ask questions.

The centre manager will advise that there is a Brain Health Clinic attached to the Brain Health Service and that the centre manager can provide more information if the person wishes.

1.1.3. People who opt for discussion with the manager

The centre manager will work through the Brain Health Questionnaire and/or review the questionnaire findings with the individual. The centre manager will signpost to relevant brain health resources, clinical services as appropriate, research participation, and the Brain Health Scotland website (specifically the 'My Brain Health' quiz).

If the person agrees, the centre manager will offer triage to a specialist practitioner led clinic appointment within the Brain Health Clinic.

1.1.4. Brain Health Clinic Triage

The level of demand for specialist practitioner and consultant led clinic appointments is as yet unknown. All referrals from either primary care or the Brain Health Service will undergo triage by the specialist practitioner and/or the Brain Health Consultant (typically this will be conducted jointly with the Brain Health Clinic specialist practitioner). The centre manager does not require to be clinically trained therefore cannot make independent decisions regarding referral to the clinic. They will put forward details of any individual who wishes to be referred to the clinic but will make it clear that the referral is subject to vetting by the specialist practitioner and/or consultant and the individual may receive a response with advice or redirection to another service if this is more clinically appropriate.

If the individual does not wish to be referred to the specialist practitioner led clinic, or this is not appropriate (e.g., an individual who is concerned about another person, or a person who does not live in the catchment area), the centre manager will offer further brain health resource signposting.

If the person has a specific single question about brain health in general, which the centre manager cannot answer, then the centre manager can offer to take written details about the person (name, contact information and query), discuss with the specialist practitioner and/or consultant, and relay the information to the person (e.g., by telephone).

The centre manager will advise that the service cannot answer specific queries about their medical records or medical conditions. The person should be referred to their GP for these queries. The centre manager will also advise that the service cannot provide information about any other person.

1.1.5. Welfare or medical concerns

If the centre manager has acute welfare concerns about a person (e.g., obvious signs of self-neglect, disclosure of unstable health conditions), the centre manager should ask permission to record personal details and information about the area of concern. The centre manager will recommend the person seek urgent advice from their GP (or from secondary care if the person is under follow-up from a relevant clinic). The centre manager will promptly escalate concerns to clinical staff. Clinical staff will determine if contact from themselves to the person is indicated, or if information should be shared with primary or secondary care services.

If the centre manager has acute welfare concerns and clinical staff are not available in a timely fashion, the manager should follow Alzheimer Scotland's relevant policies for welfare concerns of individuals attending an Alzheimer Scotland Centre, including the 'Informal Groups Safety Procedure', First Aid Policy, and the 'Adult Support and Protection Policy'.

If the manager has immediate concerns about an individual's medical wellbeing (e.g., chest pain, shortness of breath) they should contact NHS 999 or 111 services as appropriate, and alert any first aid trained staff or clinicians on site.

1.1.6. Brain health resources

All individuals will be signposted to brain health resources (both in-house and online, and from other relevant providers). Some people may prefer to access these independently, whilst others may wish for specific guidance from the centre manager.

1.1.7. Research engagement

All individuals will be signposted to general information about research participation, and specifically to the 'Join Dementia Research' participation registry. Information about relevant active local and national research studies will be available in the centre.

Further information on research engagement can be found in Section 5.

1.1.8. Future engagement

The centre manager may wish to advise the individual to return to the Brain Health Service in future to receive support in progressing their personalised prevention plan and/or for re-evaluation of suitability for the brain health care pathway.

1.1.9. Specialist Practitioner led clinic triage process

If an individual accepts an offer of triage to the specialist practitioner led clinic, the centre manager will request personal information (name, address, date of birth and contact details) and check if the Brain Health Questionnaire has been completed. People do not have to complete the questionnaire in order to be triaged, but this will be done if possible.

The centre manager will advise that an appointment is not guaranteed, and all referrals are vetted by the specialist practitioner and/or Brain Health Consultant. The proportion of interested individuals appointed to the clinic will be influenced by referral numbers and clinical need, so will vary over time depending on these factors. Additional referrals will be received from primary care and other sources, and these will be subject to the same vetting process.

Appointment decisions will be communicated to the person by the Brain Health Clinic administrator. People appointed to the clinic will be advised to bring someone who knows them well to the clinic with them, but that this is at their discretion and is not a requirement to be seen at the clinic. An informant can be very useful when assessing cognition, but some people will prefer not to disclose their concerns to significant others (or may not have an informant available) and this should not be a barrier to accessing Brain Health Clinic services.

1.2. Stage 1 Interventions

1.2.1. Personalised action plan: non-clinical

The centre manager will assist interested persons in identifying their personal brain health risk factors.

The centre manager can then make recommendations regarding managing modifiable risk factors. This could involve making lifestyle changes (e.g., cutting down or stopping smoking or alcohol intake, improving diet and exercise). For risk factors such as known diabetes or hypertension, this would take the form of reinforcing the importance of effective self-management of these conditions and attending scheduled NHS appointments.

If a person discloses difficulties with self-management (e.g., not taking medication, uncertainty about how to manage diabetes, or acknowledging they have missed scheduled NHS appointments), the centre manager will recommend they seek prompt advice from primary care (or secondary/community services if the person is already known to a service).

The centre manager can provide sign-posting advice to relevant services such as local smoking cessation services or public health services, as locally applicable.

This information will be given to any interested person, regardless of whether they wish for a referral to the Brain Health Clinic. People will additionally be signposted to the Brain Health Scotland website, in particular to the 'My Brain Health' quiz to reinforce previous discussions.

If a person does not wish for a referral to the Brain Health Clinic, the centre manager will explain that this remains an option in the future, and that people are very welcome to return to the Brain Health Service to re-discuss their risk factors or any specific brain health questions they may have.

2

Stage 2: Specialist Practitioner Clinical Assessment

2.1. Stage 2 Overview

The current recommendations reference a 'Specialist Practitioner led' clinic. The Stage 2 clinic can be staffed by a registered nurse or registered allied healthcare professional such as an occupational therapist. Brain Health Clinics can involve a range of health professions such as dietitians, nurses, occupational therapists, physiotherapists, psychologists, and speech and language therapists. The range of staff involved will depend on local workforce and available skill mix.

The specialist practitioner led clinical assessment involves firstly exploration of the patient's individual concerns and priorities. The Brain Health Questionnaire results will be reviewed (or questionnaire completed if not previously done). An assessment pack (containing questionnaires relating to mental health, sleep, and ADLs; see Section 2.2.) will be administered, as well as physical and cognitive assessments. If an informant is available, a collateral history will be taken regarding cognitive, mental health and physical functioning, in particular ADL.

This assessment is designed to identify relevant risk factors (e.g., pre-existing conditions such as obesity, hypertension, diabetes mellitus), early indicators of neurodegenerative disease, and identify potential opportunities for risk reduction and neurodegenerative disease prevention (e.g., management of comorbidities, targeted behaviour modification, social prescribing). Other targets include the evaluation of potential non-neurodegenerative causes of cognitive symptoms (e.g., sedative medications) and exploration of personal concerns or goals (e.g., discussion of genetic risk factors).

The specialist practitioner employed will be trained and skilled to commence first line interventions and referral pathways as indicated prior to consultant level discussion/review. The specialist practitioner will always have the opportunity to discuss interventions and pathways firstly with the consultant, as appropriate.

2.2. Assessment packs (questionnaires)

2.2.1. Visitor Demographics Proforma

This document captures basic personal information. This may be completed by the individual prior to referral to Stage 2. See Appendix C.

2.2.2. Brain Health Questionnaire (Edinburgh Cognitive Questionnaire)

This bespoke questionnaire captures information about common brain health risk factors. See Appendix B.

2.2.3. Hospital Anxiety and Depression scale (HADS)

The HADS is a brief validated scale for documenting symptoms of anxiety and depression (which can both cause cognitive symptoms and be due to cognitive disorders).

2.2.4. Epworth Sleepiness Index

This is a validated measure of everyday sleepiness and useful when considering sleep quality and possible sleep apnoea (a common and treatable cause of cognitive symptoms).

2.2.5. Activities of Daily Living Questionnaire (ADL)

A brief ADL questionnaire (the Functional Activities Questionnaire) will be administered to the patient (and separately to an informant, if present).

2.2.6. Family tree (family history)

A brief family tree will be drawn focusing on any history of cognitive or major psychiatric disorders.

2.3. Physical health check

2.3.1. Height, weight, and BMI

2.3.2. Blood pressure and pulse

2.3.3. Blood tests

The following blood parameters should be reviewed/obtained where possible: renal, liver, and thyroid function, full blood count, vitamin B12, folate and ferritin. Abnormalities of these blood parameters can be a cause of cognitive dysfunction. If recent results are available these tests should not be repeated unless there is a clear clinical indication. Testing for HIV and syphilis status may be clinically relevant for some individuals.

Each Brain Health Clinic must ensure there is a robust mechanism for test results being reviewed by clinical staff in a timely fashion. The exact protocol for this will vary according to local resources and protocols. Strategies for blood result review could include blood tests only being sent on a day when clinical staff are available to review the results the following day (assuming that the Brain Health Clinic is hosted out with a hospital site and therefore blood results are likely to only be ready the following day). Clinically significant abnormalities should be appropriately acted on/escalated as required in a timely fashion (the exact time scale will depend on clinical need – for example, new acute renal failure is likely to require urgent referral to hospital services, whilst vitamin B12 deficiency can typically be notified to primary care for appropriate management on a routine basis).

2.4. Cognitive assessment

2.4.1. Addenbrooke’s Cognitive Examination – Version 3

Addenbrooke’s Cognitive Examination III is a screening test that is composed of tests of attention, orientation, memory, language, visual perceptual and visuospatial skills. It is selected because it is useful in the detection of cognitive impairment, especially in the detection of Alzheimer’s disease and frontotemporal dementia.

2.5 Specialist Practitioner led interventions

The Brain Health Clinic specialist practitioner will discuss active risk factor management and make recommendations regarding strategies such as smoking cessation, refer on to relevant services e.g., diabetic clinic, public health led community services, and communicate with primary care about possible medication changes such as review of sedative agents or anticholinergics. The specialist practitioner can also make follow-up plans in discussion with selected patients (see section 2.6.3.). For some patients, a discussion with the consultant or face to face consultant review will be required before any action is taken. The specialist practitioner led clinic is also an opportunity to review advice or actions arising from the initial contact with the Brain Health Service and support the patient with continuing positive changes to their brain health risk factors.

If the specialist practitioner has acute medical or welfare concerns about an individual these will be escalated as per local NHS pathways (e.g., an individual disclosing self-harm or suicidality would be discussed with the appropriate acute mental health team).

2.6. Referral to Consultant Brain Health Clinic

2.6.1. Specialist Practitioner/ Consultant case discussion

The findings from the specialist practitioner led clinical review will be discussed at a weekly meeting between the consultant and specialist practitioner. A regular multidisciplinary team meeting is desirable to share expertise and provide feedback and learning opportunities to staff – the make-up of this will depend on local resources and clinic staffing.

The specialist practitioner will be able to discuss patients more urgently if this is felt to be clinically required.

The patient's concerns and current risk factors and assessment findings will be reviewed to determine what further action is required.

2.6.2. Consultant review recommended

It is at the discretion of the consultant as to which patients are appointed to the consultant clinic. Appropriate patients may include (but are not limited to): individuals with suspected MCI or SCD, individuals with multiple complex risk factors, individuals reporting a high level of concern about their cognition, individuals with complex questions.

The threshold for referral to the consultant clinic will be influenced by demand on the service and this is likely to evolve over time. All referrals are subject to vetting by the consultant and vetting decisions will be based on clinical need. The consultant may provide a written response to an individual or GP, or advice on there being specialist practitioner-led follow-up, or redirection to another NHS service, as is clinically appropriate.

2.6.3. Specialist Practitioner follow-up recommended

Individuals with a low level of risk factors and minimal cognitive dysfunction, with no functional limitations, can be offered specialist practitioner follow-up. We anticipate that the specialist practitioner follow-up service will target those in later mid-life and older.

Individuals who have previously seen the Brain Health consultant may also be followed up in the specialist practitioner-led clinic if appropriate (see Section 3 for further details).

2.6.4. Referral to another NHS service recommended

Following the specialist practitioner assessment, individuals with suspected dementia will be referred to their local memory clinic. If there is clinical uncertainty, these individuals can firstly be seen by the consultant.

Individuals who have other active uncontrolled issues (e.g., alcohol or substance misuse, epilepsy, other neurological disorders associated with cognitive symptoms) will be referred to the appropriate NHS service.

If there is clinical uncertainty regarding the most appropriate referral pathway, these individuals can firstly be seen by the Brain Health Clinic consultant. If necessary, these cases may be discussed with staff from other services (e.g., local neurologist or substance misuse specialist).

2.6.5. No further assessment recommended

Young adults with no evidence of cognitive or functional limitation and who do not have a complex risk factor profile or family history can be discharged. These individuals will receive a detailed personalised action plan and signposting to appropriate risk factor management resources and made aware of the option to return to the Brain Health Service if they have future concerns.

3

Stage 3: Brain Health Consultant Assessment

3.1. Stage 3: Overview

Prior to the consultant clinic appointment, the findings from the specialist practitioner appointment will be reviewed and key points of concern for the patient highlighted. In some cases, there will be specific questions or risk factors that the patient wishes to focus on, and the appointment will be geared towards these.

For most patients, the appointment will focus on reviewing the degree of cognitive symptomatology, presence, or absence of non-neurodegenerative causes of cognitive symptoms (e.g., low mood, anxiety, sleep disorders, sedative or anticholinergic medication use, functional cognitive symptoms), risk factor profile and patient wishes/ engagement in terms of risk factor modification. Clinical history and physical examination will be used in conjunction with the previously obtained information when coming to a diagnostic formulation.

3.1.1. Neuroimaging

The need for neuroimaging will be considered on a clinical basis. Individuals with no evidence of cognitive decline are unlikely to require neuroimaging.

Patients with suspected dementia can either be referred for neuroimaging by the Brain Health Clinic consultant or be referred onto the local memory clinic where a decision on the need for neuroimaging can be made.

CT should be considered for people with a history suspicious for CNS vascular disease (e.g., stepwise cognitive decline or episodes of focal neurological deficits with no prior investigations), particularly if there is no prior diagnosis of vascular disease and the patient is not already on secondary prevention medication. People with a past history of brain injury or irradiation with no prior/recent imaging may also benefit from CT or MRI to look for traumatic or atrophic findings.

MRI may be useful in selected patients, particularly when risk stratifying patients with MCI or possible very mild dementia. In these patients an assessment of medial temporal lobe volume and vascular burden may influence decision making regarding clinical follow up. Cerebral perfusion imaging such as HMPAO SPECT may be indicated for people with normal structural imaging and a high level of clinical suspicion for early neurodegeneration.

We anticipate that only a minority of patients seen at the Brain Health Clinic will be referred for neuroimaging, but this will clearly be dependent on the mix of patients being referred into the service.

3.1.2. Neurogenetics

3.1.2.i. Apolipoprotein E (APOE) status

The *APOE* polymorphism is the most significant population level genetic risk factor for ADD. It is therefore frequently used in clinical trials when selecting higher risk participants. Commercial testing for *APOE* is available to the general public via various private genomics companies.

Currently, *APOE* status does not affect diagnosis or treatment in clinical practice. Therefore, *APOE* testing for Brain Health Clinic patients is not currently recommended. However, this would change if novel therapies were licensed where only people of certain *APOE* status are eligible for treatment.

The Brain Health Clinic specialist practitioner and consultant will be able to provide advice regarding interpretation of *APOE* status results for people who have determined their phenotype via private testing (or have had this disclosed to them as part of a research study).

3.1.2.ii. Familial risk

Having a family history of dementia is frequently a cause for concern to members of the public. As part of the specialist practitioner led assessment, a basic family tree will be drawn, including information about any relatives with a cognitive diagnosis, age at onset and age at decease (see Section 2.2.6.).

For individuals with relatives who have developed dementia in later life, there is unlikely to be a significant risk of this being due to an autosomal dominant genetic condition, and the specialist practitioner or consultant will discuss this.

For anyone with a strong family history of young onset dementia (onset before 60 years) or a mixed family history of early onset dementia and major psychiatric conditions (which can be seen with some mutations, such as *C9ORF72*) the consultant will review the history and discuss if a referral to clinical genetics would be indicated. Autosomal dominant causes of dementia are rare; therefore, we do not anticipate a significant number of patients requiring specialist genetic input.

3.1.3. Biomarker assessment

There is growing interest in the use of CSF biomarkers (currently tau, phosphorylated tau, and amyloid) and amyloid and tau PET imaging when diagnosing neurodegeneration. However, their clinical use in the NHS is very restricted at the present time. CSF and PET biomarker testing are not widely available. Their clinical use is typically limited to patients with dementia, where the underlying neuropathological cause is unclear and differentiating between ADD and a different neuropathology would change clinical management, or when a patient has MCI, and it is unclear if this is due to AD or due to a non-neurodegenerative cause.

Biomarkers are widely used in clinical trials of AD therapeutics to select trial participants. It is possible that if an agent such as Lecanemab is licensed in the UK, then having positive AD biomarkers would be a requirement for patients to receive treatment.

At the present time, we do not anticipate making use of CSF or PET biomarkers in the Brain Health Clinic. In the current UK therapeutic landscape, a positive biomarker result in someone with SCD, MCI or early dementia would not alter their clinical management, therefore their use is not justified.

It is possible that some individuals might have knowledge of their biomarker status due to previous research study participation. The Brain Health Clinic consultant will be able to provide specialist interpretation and advice on these findings if needed.

3.2. Stage 3: Interventions

The consultant will risk stratify individuals regarding their current and future risk of neurodegeneration.

Some individuals will require onward referral for specific medical needs (see Section 3.3.1. for details).

If an individual is found to have MCI and/or is felt to be at increased risk of future neurodegeneration, the consultant will disclose this and discuss potential follow-up (see Section 3.3. for details).

For all patients, the consultant will review previously identified brain health risk factors. Patients may already have acted on risk factor modification following conversations with the centre manager or specialist practitioner, and the consultant will review how much progress has been made. New strategies can be suggested, or previous advice reinforced, as appropriate.

3.3. Stage 3: Follow-up Assessment and Discharge

The main priority for follow-up (either in the consultant or specialist practitioner-led clinic) is to support and observe individuals felt to be at high risk of future neurodegenerative cognitive decline, and those where the cause of their cognitive symptoms is unclear.

Where the consultant has implemented a management plan designed to improve cognition (e.g., removal of sedative agents or anticholinergics, or addition of an antidepressant) or requested investigations, individuals will benefit from consultant follow-up.

Individuals who are felt to possibly be at increased risk of neurodegenerative cognitive decline may benefit from specialist practitioner follow-up and repeat ACE-III after an interval (typically between 9 months and a year). Neurodegenerative cognitive decline tends to progress slowly hence follow-up is most useful when temporally spaced out.

Depending on local service availability, the clinic may use other modes of follow-up for low-risk individuals such as public health support with risk factor modification.

For other individuals, a referral for formal neuropsychological assessment may be appropriate. We anticipate neuropsychology referral being reserved for particularly challenging diagnoses, with follow-up plans being dependent on neuropsychological findings.

Individuals who are felt to be low risk can be discharged from the clinic with appropriate self-management advice. Individuals who have been followed up by the Brain Health Clinic for a period of time and show cognitive stability can be discharged with safety netting advice regarding seeking medical advice if cognitive symptoms worsen. The period of stability prior to discharge is at consultant discretion and will be dependent on the individual's cognitive and brain health risk profile.

3.3.1. Onward referral

The Brain Health Clinic specialist practitioner or consultant can make an onward referral to other NHS services. For those with probable established dementia this will be to the local memory clinic, or to other specialist services as appropriate (e.g., sleep clinic, brain injury rehabilitation services) or community-based services.

Some individuals will benefit from referral to social services for support at home (either for cognitive symptoms or physical difficulties) or to physiotherapy or occupational therapy. We anticipate that only a minority of patients will require onward referral for home support due to cognitive symptoms, as the profile of patients attending the Brain Health Clinic is likely to be skewed towards people with mild or no symptoms. However, co-morbidity is common, particularly in older adults, and if unmet physical needs are identified, the Brain Health Clinic specialist practitioner or consultant should refer appropriately.

4

Data pathway

4. Data pathway

High standards of data collection and protection must be maintained at all points of interaction (e.g., from walk-in or GP referral through to consultant assessment or onward referral). All patient level data will be held within NHS systems and subject to NHS governance rules. The following section provides guidance on minimum data requirements, data input for decision support tools, and data governance.

4.1. Required data

4.1.1. Stage 1 Required data

In order to monitor use (i.e., footfall) and accessibility of brain health services, basic demographic data should be recorded for all people attending an Alzheimer Scotland Centre with brain health queries. This information must remain anonymous.

Where both the centre manager and individual feel comfortable in doing so, an anonymous demographics form (see: 'Visitor Demographics Proforma'; Appendix C) should be completed. The centre manager must explain the purpose of demographics data collection, that any information provided at this stage is anonymous and unidentifiable, and that the individual is free to refuse this request.

If for any reason the centre manager or the individual do not wish to (or are unable to) complete the demographics form, the centre manager should log estimated demographic details separately (see: 'Visitor Estimated Demographics Log', Appendix D).

If triage to Stage 2 (specialist practitioner assessment) is unlikely, required data at this stage includes: age, sex, and reason for accessing brain health service. This may be provided via the demographics form or the estimated demographics form.

If referral to Stage 2 (specialist practitioner assessment) is likely, the individual should complete 'Brain Health Questionnaire' with the brain health centre manager or independently if possible (see Section 1.1., and Appendix B).

The data obtained in Brain Health Questionnaire includes the following: age, sex, height, weight, age at completion of education, highest qualification, driving status, smoking status, alcohol use, head injury history, diet, exercise, occupation, hobbies, blood pressure status, diabetes status, hearing problems, vision problems, general health appraisal, mental health appraisal, and self-reported concerns relating to brain health.

Additional data pertaining to the Equality Act (2010) may be collected via 'Visitor Demographics Proforma' (see Appendix C) if the person is willing to provide such information. This information should not be independently estimated by the brain health centre manager.

4.1.2. Stage 2 Required Data

At Stage 2 assessment, data obtained will include novel data collected at the point of assessment (e.g., through assessment pack questionnaires, physical health check, cognitive assessment) and/or data linkage through the visitor's Community Health Index (CHI) number (e.g., comorbid diagnoses).

The data required at Stage 2 assessment pertain to risk factors (demographic, family history, lifestyle, and comorbidities), and biological and clinical expression of early disease (e.g., cognition, mood, sleep). A full list of minimum required data at Stage 2 can be found in Table 1. overleaf.

Table 1. Stage 2 Data requirements

Source	Data
Brain Health Questionnaire	Age, sex, postcode, age at completion of education, smoking data (status, history, number of cigarettes per day, age/year smoking cessation), hearing and vision health, sleep, diet, exercise, weight status, family history of dementia, general health status, self-reported concern/questions regarding brain health
Hospital Anxiety and Depression Scale	Total anxiety score, total depression score
Epworth Sleepiness Scale	Total score
Activities of Daily Living	Basic ADLs score, Instrumental ADLs score
Family Tree	Family history of cognitive diagnoses and other neurological or major psychiatric disorders, age at onset of relevant family diagnoses, age at decease
Physical health check	Height, weight, BMI, blood pressure, pulse
Addenbrooke's Cognitive Examination (v3)	Total ACE-III score, attention score, memory score, fluency score, language score, visuospatial score
Data linkage/self-report	Current medications

4.1.3. Stage 3 Minimum Required Data

Stage 3 assessment involves a thorough review of data collected in stages 1 and 2. Additional minimum data required at this stage includes: working diagnosis (if appropriate), further investigation (referred for imaging, genetics), and outcome of assessment (i.e., stays in brain health clinic for follow-up, onward referral, or discharged).

4.2. Data governance

4.2.1. De-identified and anonymous data

De-identified and anonymous data may be shared among stakeholders where it is required for service evaluation, quality improvement, and clinical research. The use of de-identified data patient level data will be in line with local NHS Data Protection requirements

De-identified and anonymous data for use in clinical research must be accessed through the data safe haven, after the appropriate ethics approvals have been obtained by the researchers' local review board(s).

All Brain Health Service and Clinic staff should make themselves familiar with Alzheimer Scotland's data and privacy policies, the local NHS board's own requirements for data protection and privacy, and with national data protection and privacy law (e.g., GDPR).

4.2.2. Identifiable data

It is not expected that any identifiable information should be routinely collected unless a person is expected to progress to a Stage 2 specialist practitioner assessment. In this instance, data collected must only be accessible to the centre manager at point of collection and to Brain Health Clinical practitioners. This data must be stored securely (e.g., hard copies should be stored in a locked filing cabinet, to be retrieved only by clinical staff. Online records should be stored on Alzheimer Scotland's SIS programme).

The centre manager may have access to the secured data storage location (physical or access of SIS records) for the purpose of storing data they have obtained and to provide data to approved requestors (i.e., clinical staff). The centre manager must not access these data for any other purpose.

Occasionally, a prospective patient of a brain health clinic may require contact from the Brain Health Clinic specialist practitioner or consultant (see Section 1.1.4). In this instance, contact information may be collected by the centre manager and passed on to the relevant practitioner. This information must remain confidential. This information should not be retained beyond this purpose and should be securely destroyed when no longer required.

As with non-identifiable data, identifiable data must only be collected and stored in strict adherence to local NHS protocols and must adhere to GDPR and all other relevant data protection law.

5

Research Environment

5.1. Research registration

Every person who enters a Brain Health Service and Clinic is eligible to register on the 'Join Dementia Research' (JDR) participant panel and on NHS Research Scotland's Neuroprogressive and Dementia Network register.

JDR connects researchers with potential research participants, from healthy adults to individuals with cognitive complaints and diagnosis of dementia. JDR registry is available online, by phone, or by completing a form. JDR registration forms and information leaflets will be made available at the Brain Health Service and Clinic.

NHS Research Scotland's Neuroprogressive and Dementia Network provides a similar service to JDR, with research participation opportunities localised to Scotland. Registrants are requested to provide their CHI number for this participant panel. Registration can be completed via the 'Consent to Contact' form, available as a paper form and online. Information leaflets and consent to contact forms for the Neuroprogressive and Dementia Network will be made available at the Brain Health Service and Clinic.

The Neuroprogressive and Dementia Network also provide participants with an opportunity to shape and refine research in Scotland. Interested parties can register to participate in the Partners in Research panel online..

JDR:

https://www.joindementiaresearch.nihr.ac.uk/

Neuroprogressive and Dementia Network:

https://www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease/get-involved

5.2. Local and national research programmes

Research groups may opt to contact the Brain Health Service or Brain Health Clinic with requests for research participation directly. Such requests should be discussed among the local team, and approval for centre participation must ensure research groups have followed local and national guidelines for research projects (including ethical approval by the appropriate institutional review board(s), information and consent documentation, and data use plans).

5.3. Willingness to innovate.

Scotland's Brain Health Clinics represent the first national brain health care pathway worldwide. As pioneers of clinical practice in brain health, clinic staff and their Alzheimer Scotland partners should be enthusiastic about trailing innovative and novel approaches to brain health promotion, early disease detection, and, when appropriate, early intervention. There may be occasions where a centre is requested to participate in trials of technologies, therapies, and other aspects of clinical practice which may not have an established evidence base, due to the relatively 'young' nature of brain health clinical research. Trials of innovative methods may provide no direct benefit to patients of the local brain health clinic but may provide valuable insights into approaches that may work elsewhere in Scotland.

Practitioners should feel confident and be supported in raising legitimate concerns regarding innovation requests but should not dismiss requests without appropriate consideration.

6

Audit and Service Evaluation

6. Audit and Service Evaluation

6.1. Non-clinical audit

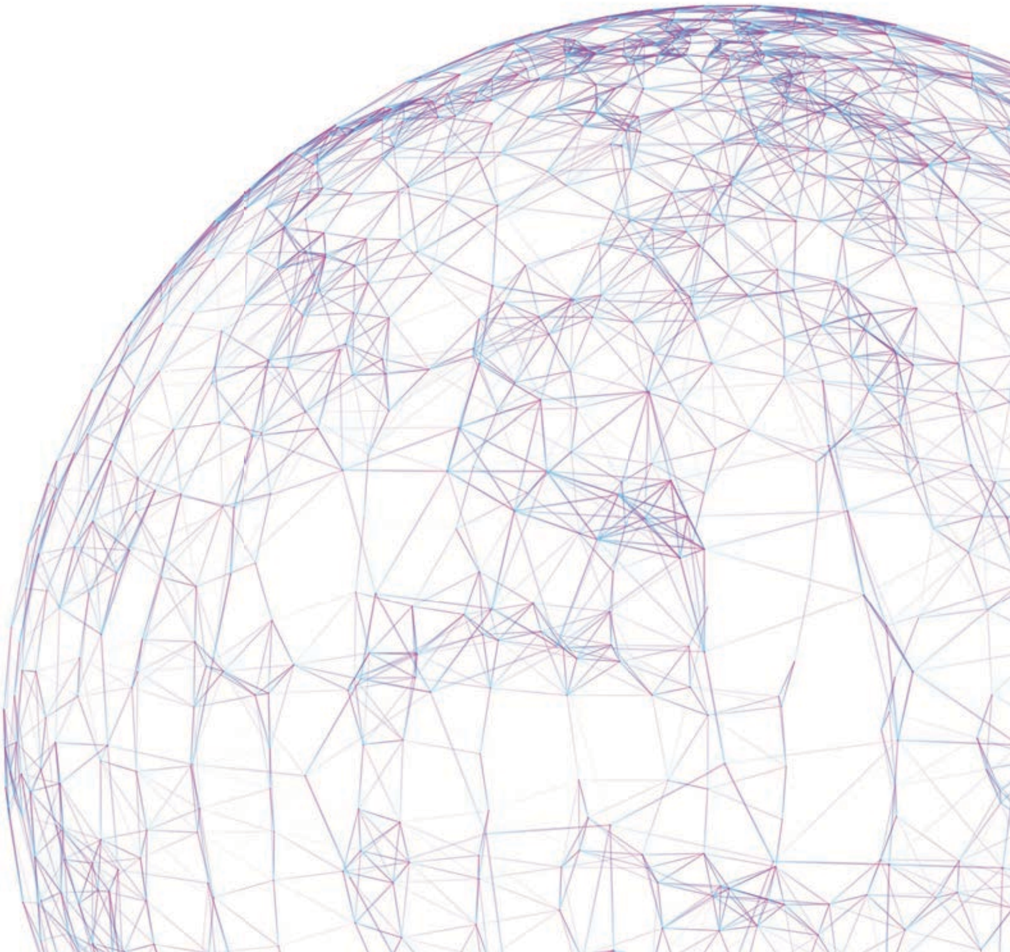
Non-clinical audits will utilise data that are collected for equality and diversity purposes, to provide an opportunity to analyse how the Brain Health Service and Clinic is used, and for people to provide anonymous feedback.

Non-clinical audit data will be derived from the minimum required data outlined in Section 4.1.1, and from anonymous feedback forms.

6.2. Clinical audit

Clinical audits will aid in assessing the clinical efficacy of Brain Health Clinics and highlight areas for quality improvement. Planned collation of all relevant documents (see Section 4.1.) will allow NHS audit or service evaluation to take place in a streamlined fashion. A pre-specified spreadsheet will be used to capture information about patients attending the Brain Health Clinic. This spreadsheet is designed by Brain Health Scotland for use in NHS audit, and all populated spreadsheets will solely be stored on the local NHS server (see document 'Brain Health Clinic audit template' for details). The spreadsheet can be adapted in line with local NHS quality improvement guidelines and local needs. The specialist practitioner and consultant will update the audit document following clinic visits. Local NHS quality improvement guidelines will be followed prior to anonymised summary data being shared outside the NHS.

To access the latest version of the spreadsheet please contact Brain Health Scotland on brainhealth@alzscot.org



7

Equity of Access

7.1. Service access considerations for individuals

7.1.1. Equity versus equality

The Alzheimer Scotland Centre and Brain Health Clinic must make every effort to ensure that the service provided caters appropriately to all individuals. The Scottish Model for Brain Health is fundamentally based on equity of access, by making accommodations which will vary by individual need. This is opposed to a model of 'equality of access', wherein all people would be provided with an identical service, regardless of individual differences in need.

Specific considerations will not only vary by individual person or patient but will likely look different in different regions of Scotland. For example, larger cities may have a greater population of individuals for whom English is a second language.

7.1.2. Equality Act (2010) protected characteristics

Protected characteristics, as defined in the Equality Act (2010) include: age, disability, gender reassignment, marriage and civil partnership, race, religion or belief, sex, and sexual orientation. Legal protection from discrimination also applies to pregnancy and maternity. Alzheimer Scotland Centre staff and Brain Health Clinic practitioners should be familiar with the Equality Act (2010) and local policy relating to protections from discrimination.

7.1.3. Equality, Diversity, and Inclusivity training

Practitioners and staff within Alzheimer Scotland Centres and Brain Health Clinics should maintain an awareness of best practice in what is commonly referred to as 'equality, diversity, and inclusivity' (EDI). Alzheimer Scotland staff should refer to Alzheimer Scotland training in this area, and practitioners should refer to their local NHS board training requirements.

7.1.4. Understanding bias in clinical research and practice

Practitioners must remain mindful of the inherent bias in clinical research and guidance based on research conducted predominantly within these populations.

In assessing brain health in individuals of any background, consideration should be given to the ways in which the individual's environment and personal history may have impacted their neurodevelopment, their general health, and their current clinical presentation. There is currently limited guidance available on how or whether clinical measures (e.g., cognitive testing) can or should be adjusted to individual circumstances, and so practitioners must rely on their informed clinical judgement.

7.1.5. "No ought without support"

A large proportion of risk factor modification relies on personal risk management. This largely involves 'lifestyle' adjustments, but also extends to keeping appointments and medication adherence. There are innumerable reasons why personal risk management may be challenging to an individual, regardless of whether they possess a protected or underrepresented characteristic or not. For brain health interventions to be successful and sustainable, brain health clinical practice should adopt a "no 'ought' without support" standpoint: risk factor modifications (i.e., actions a person or patient 'ought' to undertake) should not be recommended where the practitioner and patient are unable to reach an agreement as to how the patient will be supported in achieving required modifications.

In the first instance, the centre manager or practitioner and the person or patient should co-develop a 'personalised action plan'. This should include specific and attainable proposed actions (e.g., taking medication to control hypertension, exercising for 30 minutes three times a week), time frames in which these actions should be undertaken, and a named service or person who is responsible for supporting the person or patient in achieving their goals.

Some people may require enhanced support in achieving their personalised action plan. Additional support, such as offering more frequent follow-up with practitioners (e.g., nurses, allied health professionals) or a greater emphasis on joining an established support group, should be considered in individuals who have a limited social support network. Any enhanced support should be agreed upon with the person or patient.

7.2. A population approach to widening service access

Health inequalities are often compounded in individuals with one or more protected characteristic, in individuals from deprived socioeconomic backgrounds, in individuals with care experience, experience of incarceration, experience of seeking asylum, and experience of multiple adverse life events. Significant effort should be made to ensure the service is accessible to people within these groups, who may be less inclined to inherently trust healthcare providers and other institutions.

The way in which effort is made to provide an equitable service will vary by region. Alzheimer Scotland Centre and Brain Health Clinic staff should consult with experts in their region to develop suitable approaches. 'Experts' may include people with lived experience from varying backgrounds, and individuals with academic or clinical expertise in working with underrepresented groups.

Enhanced efforts to reach in to underrepresented groups may include (but are not limited to) hosting information events within communities, ensuring information relating to brain health and Brain Health Clinics is available within a broad range of community settings, and ensuring a variety of methods of presenting information to the community (e.g., mix of digital and paper-based media) is available.

7.2. Evaluating equity of access

An anonymous 'Visitor Demographics Proforma' (see Appendix C) will be supplied to Alzheimer Scotland Centres and Brain Health Clinics. This form includes questions pertaining to protected characteristics, enabling completion of Equality Impact Assessments and analysis of equity of access. People accessing the Brain Health Service and Brain Health Clinic may also wish to provide anonymous feedback.

There is limited data on the majority of protected groups in relation to accessing brain health services. The lack of data is due to the novelty of brain health care pathways, but also due to a broader lack of data collection in this area in other brain-health-related clinical services, such as cognitive assessment and stroke clinics. Therefore, it is not advised that any specific target for service access by any population should made at this time (i.e., it is not advised that a brain health clinic should specifically aim to reach a certain proportion of a certain population).

When a Brain Health Clinic has been operational for some time, staff may wish to consider developing a patient and public involvement (PPI) panel, or hosting a series of PPI focus groups, to provide further feedback on the perceived accessibility of the service. In this instance, every effort should be taken to involve individuals who have not attended the Brain Health Service or Brain Health Clinic to limit sampling bias.

8

Staff Training and Resources

8.1. Centre managers and other non-clinical colleagues

Alzheimer Scotland staff, including the centre manager and other non-clinical colleagues, will receive training relating to brain health from BHS/AS. All staff should feel confident in signposting people who enter the Alzheimer Scotland centre to information about brain health, and at least basic information as to what the brain heath care pathway entails.

These recommendations have been written with the assumption that the centre manager is not clinically trained. There is no barrier to the centre manager being a clinical member of staff but is likely that in many areas the centre manager will be non-clinical. The centre manager will receive training using various vignettes providing examples of potential interactions with individuals accessing the Brain Health Service and the Brain Health Clinic.

8.2. Multi-disciplinary team meetings (MDTs)

The Brain Health Clinic specialist practitioner and consultant will meet on a weekly basis to discuss their current caseload. A regular clinical staff multi-disciplinary team meeting is desirable to share expertise and provide feedback and learning opportunities to staff – the make-up of this will depend on local workforce and clinic staffing.

Clinical staff may wish to meet with the centre manager, Brain Health Clinic administrator, and practitioners (e.g., allied health professionals) within the Alzheimer Scotland Centre to discuss matters arising on a regular basis. This should not include information relating to individuals or patients, but may include identifying training requirements, additional signposting information or resources, and monitoring whether referrals into the Brain Health Clinic remain manageable.

8.3. Brain health clinic network-wide MDTs

It is vital that Brain Health Clinics provide a comparable service across the country to avoid a 'postcode lottery'. As further Brain Health Clinics are established across Scotland, Alzheimer Scotland Centres and Brain Health Clinics may wish to meet for network-wide symposia for knowledge exchange and to discuss matters arising within their local services. Future iterations of Brain Health Services Recommendations for Clinical Practice should include finer detail on when and how network-wide meetings are conducted.

8.4. Additional resources

8.4.1. The Scottish Model for Brain Health

It is recommended that the centre manager and practitioners within the Brain Health Clinic are familiar with the Scottish Model for Brain Health.

Ritchie, C.W., Waymont, J.M., Pennington, C., Draper, K., Borthwick, A., Fullerton, N., Chantler, M., Porteous, M.E., Danso, S.O., Green, A. and McWhirter, L., (2022). The Scottish Brain Health Service Model: Rationale and Scientific Basis for a National Care Pathway of Brain Health Services in Scotland. *The Journal of Prevention of Alzheimer's Disease*, Vol 2(9) pp.348-358

This can be accessed freely at the following address: https://doi.org/10.14283/jpad.2021.63

8.4.2. Lancet Commission on Dementia prevention, intervention, and care.

Alongside the Scottish Model for Brain Health, much of the content of these recommendations is based on evidence provided in the 2020 Lancet Commission on dementia prevention, intervention, and care. Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C. and Costafreda, S.G., 2020. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, Vol 396, pp.413-446.
This can be accessed freely at the following address: https://www.thelancet.com/article/S0140-6736(20)30367-6/fulltext

8.4.3. Understanding Brain Health: Preventing Dementia

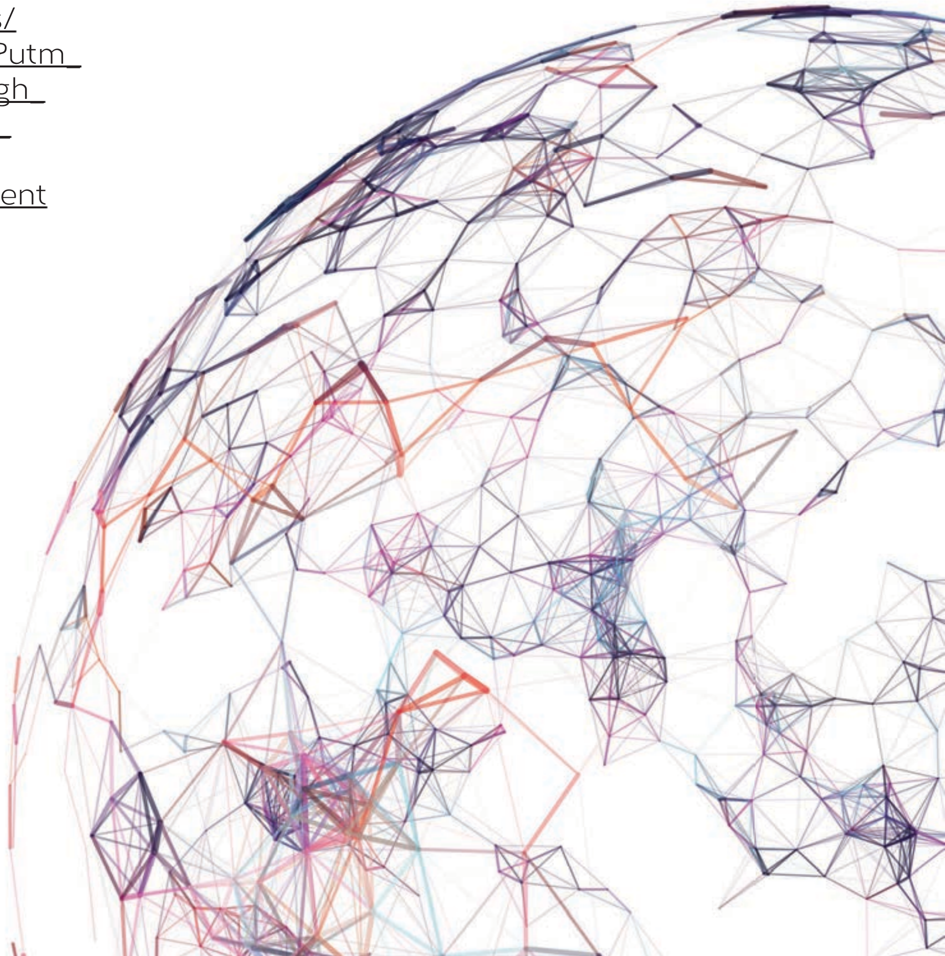
Staff of the Alzheimer Scotland Centre and Brain Health Clinic may wish to complete the free, online course developed by Brain Health Scotland and the University of Edinburgh: *'Understanding Brain Health: Preventing Dementia'.*

https://www.futurelearn.com/courses/understanding-dementia-prevention?utm_campaign=the_university_of_edinburgh_understanding_dementia_prevention_march_2021&utm_medium=organic_email&utm_source=newsletter_segment

8.4.4. Scottish Dementia Research Consortium

Alzheimer Scotland Centre staff and Brain Health Clinic practitioners may wish to become members of the Scottish Dementia Research Consortium (SDRC). Membership is free, and open to everyone who participates in dementia and brain health research or clinical practice, including researchers, clinicians, people with lived experience, and interested members of the public.

The SDRC host an annual research conference. This event typically includes presentations from early career researchers, individuals with lived experience of dementia (including caregivers), from other research communities, and from clinicians. It is a worthwhile experience for those wishing to gain an insight into the current brain health and dementia research landscape in Scotland.



Appendices

Appendix A: Clinical Vignettes

Brain Health Service

Non-clinical staff will not make decisions about who to offer a Brain Health Clinic referral to and should have a low threshold for discussing any concerns with the clinical team.

Clinical Vignettes

These hypothetical scenarios are designed to illustrate some common potential scenarios in terms of the possible participants attending the Brain Health Service.

They are written for training purposes only.

A) **70-year-old woman who is worried about her memory**

A 70-year-old lady attended the Brain Health Service alone. She says that she is worried about her own memory and thinking.

She is scared that she might be developing dementia and would like to talk to someone about her symptoms.

Guidance This person is an older adult who has memory and thinking symptoms which are causing them concern. It would be appropriate to offer them referral for a specialist practitioner appointment and gather more information for this.

Offer referral to the specialist practitioner (explaining that an appointment is not guaranteed, and another option would be for her to talk to her GP).

Gather information via the Brain Health Questionnaire.

Dementia is very common in older adults. If someone over 65 years has memory or thinking symptoms which are worrying to them (or their friends/family) then it is appropriate to offer a specialist practitioner appointment.

B) **A 35-year-old man who is interested in learning more about brain health**

This 35-year-old man attends the Brain Health Service with his partner. He and his partner are trying to make healthy lifestyle changes after an older relative was diagnosed with dementia. They also ask about how having a relative with dementia affects your risk of getting dementia.

Guidance: suggest they both work through the Brain Health Questionnaire. Ask if there are particularly risk factors, they would like to find out more about and offer relevant information. Signpost to specific support services (e.g., smoking cessation) if relevant. Signpost to GP if relevant (e.g., concerns about blood pressure or diabetes).

Having a relative who develops dementia when older (over 65 years at onset of symptoms) does not usually indicate a raised personal risk of developing dementia. This is because dementia is very common as we get older. There are rare types of genetic dementia syndromes which run in families, but these usually affect people in middle age or younger. If a person reports a family history of dementia in a young/mid-life relative, or they are very worried about their family history then an offer of a specialist practitioner appointment is appropriate. For people with relatives affected in older life, an offer of written information about dementia genetics is appropriate.

A younger adult who does not have any symptoms and attends the Brain Health Service because they are interested in learning more about their brain health is unlikely to need a specialist practitioner appointment.

C) **A 25-year-old man who is worried about possible attention deficit hyperactivity disorder (ADHD)**

This 25-year-old man attends the Brain Health Service because he is worried about his attention and memory. He is concerned that he has undiagnosed ADHD.

Guidance: signpost to appropriate local services (this is likely to be via their GP in the first instance). ADHD requires specialist assessment which is out with the scope of the Brain Health Service and Clinic.

D) **A 55-year-old man who is worried about his memory**

A 55-year-old man attends the Brain Health Service alone. He is worried about his memory and thinking. After guiding him to the Brain Health Questionnaire he discloses a high level of alcohol use.

Guidance: Advise that alcohol use can cause memory and thinking symptoms. The main priority should be safely managing his alcohol use. Ask him if he has discussed his alcohol use with his GP or other NHS service. If he has not had professional advice, signpost him to appropriate services. If he is already in contact with a service about his alcohol use, suggest he contact them.

Do not give any advice about cutting back or stopping drinking to someone with high alcohol use. Stopping or cutting back suddenly can be dangerous and should only be done under medical supervision.

A similar approach should be taken to someone who discloses street drug use. It is very difficult to assess memory and thinking whilst someone is actively using a high level of alcohol or street drugs, as these have a significant effect on memory and thinking. The first step for an individual is engaging with professionals to help manage their alcohol or street drug problems.

E) **A 75-year-old lady with signs of self-neglect**

A 75-year-old lady attends the Brain Health Service alone. She is worried about her memory. She reports living alone and having no family locally. She appears rather muddled about whether or not she has spoken to her GP and volunteers a lot of personal information. She comes across as being a vulnerable adult. There is evidence that she may not be self-caring well, she looks underweight, and there are stains on her clothing.

Guidance: This lady may have undiagnosed memory problems, and there are signs that she is vulnerable and in need of more support at home. She would benefit from review by her GP and at the Brain Health Clinic. If there is clear evidence of memory impairment, then clinical staff at the Brain Health Clinic can refer her on to the local Memory Clinic. If there is another cause of self-neglect the clinical staff can refer her for appropriate support. Given that there are signs of possible self-neglect it would be appropriate to highlight this in her Brain Health Clinic referral, so clinical staff can update her GP.

F) **A 70-year-old man whose wife has a dementia**

A 70-year-old man attends the Brain Health Service with his daughter. His wife has recently been diagnosed with dementia and he is looking for information about dementia and more support at home. His daughter is wondering if there is anything she can do to reduce her risk of getting dementia.

Guidance: Guide the man to Alzheimer's Scotland services to obtain information about dementia and support.

Suggest his daughter work through the Brain Health Questionnaire. Offer further information about relevant risk factors. Offer information about dementia genetics.

Key points: a friend, family member and/or carer for someone with dementia who is looking for further information and support is more likely to benefit from talking to Alzheimer's Scotland directly than the Brain Health Clinic.

G) **A 35-year-old woman who is worried about her family history**

A 35-year-old woman attends the Brain Health Service alone. She is worried about her risk of dementia because her mother was diagnosed with dementia when she was 45 years old and died within 5 years of her diagnosis. Her mother's brother was recently diagnosed with dementia in his late 50s.

Guidance: Having family members who develop dementia at a younger age (under 65 years of age) is unusual. This can suggest that there might be a genetic cause for the dementia. Offer a referral to the Brain Health Clinic specialist practitioner for further discussion.

Most people who report a family history of dementia will have relatives who are affected in late life (onset of dementia at 65 years old or more). Dementia is very common in older adults and the large majority of cases are not due to a genetic mutation. Having family history of relatives developing dementia in late life does not suggest that someone is at increased of developing dementia themselves.

Description	Pathway	Explanation
Well, independent adult, any age. Few risk factors. Interested in maintaining their brain health.	Centre manager signposting regarding risk factor management and general brain health promotion.	This person is at low risk of having current neurodegeneration. They will benefit from self-management of their brain health.
Adult of any age. Multiple risk factors OR complex risk factors (e.g., diabetes with complications, previous stroke).	Offer a specialist practitioner appointment. Signposting to NHS services for uncontrolled medical issues.	This person is at increased risk of future neurodegeneration. They will benefit from clinical review of their risk factors, and clinical management of uncontrolled medical issues.
Adult over 60 years. Worried about their cognition.	Offer a specialist practitioner appointment. Check for any welfare concerns.	Regardless of risk factors, older adults are at increased risk of neurodegenerative cognitive decline. Specialist practitioner assessment is appropriate. If welfare concerns are present an early referral to other services may be needed.
Adult over 60 years. They are not concerned, but a significant other attending with them raises concerns about their cognition.	Offer a specialist practitioner appointment. Check for any welfare concerns.	People with neurodegeneration may lose awareness of their cognitive symptoms – meaning they report no or minimal symptoms whilst others raise concerns.
Individual with significant psychiatric symptoms of depression/anxiety type.	Recommend GP review. Discuss directly with specialist practitioner or Consultant if any concerns. Check for any welfare concerns suggesting urgent NHS support needed.	Uncontrolled mental health problems can cause cognitive symptoms. The priority is to treat the mental health symptoms.

Description	Pathway	Explanation
Adults with new behavioural change (reported by self or significant other), e.g., inappropriate behaviour, hallucinations, apathy.	Discuss with Consultant – may benefit from Brain Health Clinic appointment but may be more appropriate for GP or old age psychiatry review. Check for any welfare concerns suggesting urgent NHS support needed.	New behavioural change can be due to rare types of neurodegenerations such as frontotemporal dementia. However, this could also be a different psychiatric condition and individual cases should be discussed with the doctor.
Adult who is concerned they may have a condition such as autism, ADHD, dyspraxia.	Signpost to relevant NHS service.	
Adult who is worried about their own family history of dementia	Enquire how old relatives were at the onset of their dementia (see guidance). Offer referral to Brain Health Clinic.	
Adult with signs of self-neglect	Self-neglect may result in weight loss, lack of self-care (personal hygiene, stained clothing, or clothing inappropriate for the weather). This can be because the individual is a vulnerable adult. For anyone with signs of possible self-neglect, the centre manager should seek personal details and raise concerns with clinical staff.	For any suspected vulnerable adult, the clinical staff should flag this to their GP and consider if a Brain Health Clinic appointment is indicated. Self-neglect can have multiple causes – this could be due to cognitive decline, but there are many other possible causes.

Appendix B: Brain Health Questionnaire (Edinburgh Cognitive Risk Factor Questionnaire)

Edinburgh Cognitive Risk Factor Questionnaire

Many different areas of our lives can influence our brain health. Please fill in this questionnaire as completely as you can.

How old are you? .... **Sex:** ☐ MALE ☐ FEMALE

Height .... **Weight** ....

Education:

How old were you when you left school? ....

What is your highest qualification?

☐ None ☐ School exams (please state type)

☐ University degree ☐ Higher degree (PhD or MD)

☐ Other (please state) ....

Driving:

☐ Current driver ☐ Never driven

☐ Used to drive but now stopped because of ....

....

Cigarette smoking:

☐ Never smoked

☐ Ex-smoker How many a day?: .... Age started: .... Age stopped: ....

☐ Current smoker: How many a day? ....

Alcohol: How many units of alcohol do you have a week? ....

Head injury: Year ....

What happened? ....

....

Did you lose consciousness (black out)? ☐ YES ☐ NO

Do you have any memory loss (amnesia) for the injury? ☐ YES ☐ NO

Diet: How many portions of fruit and veg do you eat a day? ....

Exercise: Please tick the statement which describes you best.

☐ I don't do any exercise in a typical week.

I do light exercise (for example, light walking, swimming or stretching):

☐ Once a week ☐ Twice a week ☐ 3 times a week or more

I do moderate or strenuous exercise:

☐ Once a week ☐ Twice a week ☐ 3 times a week or more

Work: What is your current or last job? ....

Do you have any hobbies? ....

....

Blood pressure:

☐ Do you have high blood pressure (hypertension)?

☐ Do you take medicine to treat high blood pressure?

Diabetes: Do you have diabetes? ☐ YES ☐ NO

Family: Have any of your family been affected by dementia? ☐ YES ☐ NO

If yes: Who was affected and how old were they? ....

....

Do you have any hearing problems? ☐ YES ☐ NO

Do you have any visual problems? ☐ YES ☐ NO

How is your general physical health?

☐ VERY GOOD ☐ GOOD ☐ OK ☐ POOR ☐ VERY POOR

Do you have any mental health concerns? ....

....

Do you have any concerns or questions about your brain health? ....

....

NOTES FOR QUESTIONNAIRE COMPLETION:

Prior to providing the questionnaire, please advise that individuals are welcome to leave any questions blank if they prefer. If an individual is unsure regarding how to estimate units of alcohol per week, this online calculator can be used: Unit calculator | Alcohol Change UK

https://alcoholchange.org.uk/alcohol-facts/interactive-tools/unit-calculator

Appendix C: Visitor Demographics Proforma

Visitor Demographics Proforma

We collect **anonymous** information about how our brain health hubs are used. This is so that we can improve the service in future.

Any information written on this form is provided voluntarily. If you do not wish to provide any information, please return the form to the brain health advisor.

This proforma can be completed by a brain health advisor with the visitor, or the visitor may wish to complete the proforma alone.

Information provided in this proforma will remain anonymous. Please do not provide any details which might identify you.

You should complete this form with information **about yourself**, even if you are visiting to seek advice for a friend or family member.

Location of brain health hub: ……………………………………………………………………………

Month and year of visit [mm/yyyy]: …………………… /……………………

Age

Please complete either exact age or indicate age group, as preferred. **Age (years):** ……………………

Age grouping:

Under 30 ☐ 30 to 49 ☐ 50 to 59 ☐ 60 to 69 ☐ 70 to 79 ☐ 80 to 89 ☐ 90+ ☐

Prefer not to say ☐

Sex

Male ☐ Female ☐ Prefer not to say ☐

Reason for visit

Advice/information for myself ☐ Advice/information for a family member/friend ☐

Se;eking appointment for myself with nurse ☐

Seeking appointment with nurse for friend/family ☐

Another reason ☐

Please write in: ……………………………………………………………………………

The following information which relates to characteristics protected by the Equality Act (2010).

This information is requested to ensure we are providing a fair service to everyone who visits us. If you do not wish to provide any of the following information, please return the form to the centre manager.

Ethnicity

White ☐
(e.g., White Scottish/English/Welsh/Northern Irish/British/Irish, White gypsy/traveller, White Polish, any other white ethnic group)

Asian, Asian Scottish, or Asian British ☐
(e.g., Pakistani/Pakistani Scottish/Pakistani British, Indian/Indian Scottish/Indian British, Bangladeshi/Bangladeshi Scottish/Bangladeshi British, Chinese/Chinese Scottish/Chinese British, any other Asian ethnic group)

African, Caribbean, or Black ☐
(e.g., African/African Scottish/African British, Caribbean/Caribbean Scottish/Caribbean British, Black/Black Scottish/Black British, any other African, Caribbean, or Black ethnic group).

Mixed or multiple ethnic groups ☐
Please write in ....

Other ethnic group ☐
Please write in ....

Prefer not to say ☐

Religion

None ☐ Church of Scotland ☐ Roman Catholic ☐ Other Christian ☐
Muslim ☐ Hindu ☐ Buddhist ☐ Sikh ☐ Jewish ☐ Pagan ☐
Other (please write in): .... Prefer not to say ☐

Marital status

Never married/Never in a civil partnership ☐ Married/In a civil partnership ☐
Divorced/Separated ☐ Widowed ☐ Prefer not to say ☐

Disability

Do you consider yourself to have a disability?
Yes ☐ No ☐ Prefer not to say ☐

Sexual Orientation

Straight (Heterosexual) ☐ Gay or lesbian ☐ Bisexual ☐ Prefer not to say ☐
Other (please write in): ....

Gender Identity

Do you consider yourself to be trans? Yes ☐ No ☐ Prefer not to say ☐

Appendix D: Estimated Visitor Demographics Log

This log should be completed by the centre manager for all visitors to the centre seeking brain health advice or referral to the brain health clinic. Where possible, the advisor should request the visitor complete a Visitor Demographics Proforma.

Age group: under 30/30-39/40-49/50-59/60-69/70-79/80-89/90+/Unknown
Sex: F/M/Unknown
Reason for visit: Seeking advice for self/Seeking advice for someone else/Seeking appointment

Location of brain health hub: ……………………………………………………………………

Month/Year	Age group	Sex	Reason for visit
05/2023	*50-59*	*F*	*Info for self*

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November 2023