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Validation of Welsh language cognitive assessment tools (CATs): stage one

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Validation of Welsh language cognitive assessment tools (CATs): stage one

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Validation of Welsh language cognitive assessment tools (CATs): stage one

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Views expressed in this report are those of the researcher and not necessarily those of the Welsh Government

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Glossary

ACE-III

Addenbrooke's Cognitive Examination-III

AMTS

Abbreviated Mental Test Score

CAT(s)

Cognitive Assessment Tool (s)

GP

General Practitioner (primary care)

GPCOG

General Practitioner Assessment of Cognition

IAITH

Welsh centre for language planning

IQCODE

Informant Questionnaire on Cognitive Decline in the Elderly

LLAIS

At the time of writing this report, the Language Awareness Infrastructure Support. LLAIS website micym.org offered information about health measures available in Welsh, their access details and licensing arrangements.

MAS

Memory Assessment Services

Mini-Cog

Mini Cognitive Assessment Instrument

M-ACE

Mini-Addenbrooke's Cognitive Examination

MIS

Memory Impairment Screen

MMSE

Mini Mental State Examination

MoCA

Montreal Cognitive Assessment

NHS

National Health Service

NICE

The National Institute for Health and Care Excellence

10-CS

10-point Cognitive Screener

SIS

6-item Screener

6CIT

6-item Cognitive Impairment Test

RBANS

Repeatable Battery for the Assessment of Neuropsychological Status

TYM

Test Your Memory

1. Introduction

In 2021, the Welsh Government commissioned IAITH, in partnership with Bangor University, to undertake the first stage of research into the validation of Welsh language Cognitive Assessment Tools (CATs). This report reviews the tests used in Memory Assessment Services (MAS) across Wales for diagnosing dementia between October 2021 and May 2023. It highlights the progress made in validating Welsh language CATs and lays the groundwork for future efforts to ensure accurate and culturally appropriate dementia diagnoses, ultimately improving care for those affected in Wales.

On 1st April 2024, there were 23,770 people aged 65 or over registered with GP practices in Wales who were diagnosed with dementia. However, as a number of people are likely to have dementia who have not yet been formally diagnosed, the total number of people with dementia in Wales is estimated to be 42,426¹. This means that 56% of those 65 and over with dementia in Wales are likely to <u>have received a diagnosis</u>. Accurate diagnosis is crucial for providing appropriate care and support, ensuring patients receive the right treatments and interventions to significantly improve their quality of life.

1.1. Context

The "More than just words" strategic framework, <u>first published in 2012</u> and <u>updated in 2016 and again in 2022</u>, highlights the necessity of providing services in Welsh to enhance care quality. The <u>Dementia Action Plan 2018-2022</u> further recognises that for Welsh speakers living with dementia, receiving care and support in their first or preferred language is a clinical need. As their condition progresses, bilingual people with dementia may understand or be able to communicate in only one language (Welsh Government, 2018:31).

The subsequent Welsh Government document on <u>strengthening provision in response to COVID-19</u> (Welsh Government, 2021) also recognises the need to 'work with stakeholders to identify and utilise the most robust clinically validated dementia assessment tool(s) for use in the Welsh language and commission research as necessary' (2021:10). The <u>current More Than Just Words Five Year Plan 2022-27</u> reiterates that 'receiving services in Welsh is often a matter of need. This is especially true for those with dementia where it is vital that assessments can be provided in Welsh' (Welsh Government, 2022:4).

In 2013, the Alzheimer's Society approached <u>LLAIS</u> (<u>Language Awareness Infrastructure Support, Bangor University</u>) to translate the Cognitive Assessment Toolkit for Clinicians into Welsh and to undertake a linguistic validation of three assessment tools included in the toolkit: the Montreal Cognitive Assessment (MoCA), the Addenbrooke's Cognitive Examination-III (ACE-III), and the General Practitioner Assessment of Cognition (GPCOG). At that time, these three tests were considered the most widely used cognitive assessments in MAS in Wales.

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¹ The diagnosed measure is based on individuals registered with Welsh GPs, which may include some English residents. However, the estimate for both diagnosed and undiagnosed cases is based on the Welsh population.

Other cognitive assessments that have been translated to Welsh, but not by LLAIS, include: the brief Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) (Roberts et al., 2010), the pre-morbid IQ test, and Spot the Word (Clare et al., 2017).

The cognitive assessment tools translated into Welsh by LLAIS followed best practice for translation and linguistic validation as recommended by Wild et al. (2005). This involved a thorough, iterative process of translating from English to Welsh and then back to English, along with consultations with users of the test, to ensure consistency and equivalence in both language versions. However, psychometric validity testing to confirm the accuracy and suitability of these measures in Welsh has not yet been conducted.

Two people with the same degree of cognitive impairment should achieve the same result from a cognitive test, irrespective of the language of the assessment. Therefore, consideration needs to be given to the possibility that, without psychometric validation of the Welsh language version, some of the tests in Welsh may overestimate or underestimate the extent of the cognitive impairment compared to the same tests in English.

1.2. About this study

The primary aim of this research (stage one) is to identify the most frequently used Welsh language CAT in Wales. This information will be used to establish the requirements and set the foundation for subsequent stages of validation.

The primary objective of this research is to perform a desk-based review and engage with stakeholders to:

- determine the most frequently used CAT(s) in Wales during the study period (2021 to 2023)
- evaluate the psychometric properties of the CATs that have been translated into Welsh
- identify strategies for gathering high-quality normative data on the most frequently used, robust Welsh-language version(s) of CATs to ensure psychometric validation and facilitate reliable interpretation of assessments in clinical settings

The remainder of this report is structured as follows:

- Section 2: methodology used for the desk-based review and consultation with stakeholders
- Section 3: main findings
- Section 4: conclusions
- Section 5: recommendations for further validation work.

2. Methodology

This section provides an overview of the methodology used for the desk-based review and stakeholder engagement undertaken during the first stage of validating Welsh language CATs.

2.1. Method used for the desk-based review

The review, conducted between February and May 2022, involved a systematic examination of UK guidelines that endorse the use of CATs in various dementia care settings, including initial GP assessments, MAS, acute care settings, and care homes across Wales.

The review examined the psychometric properties of each test mentioned in the UK guidelines.

The quality and rigour of the CATs was examined by examining each test's psychometric properties. The main psychometric properties reviewed were:

- reliability: the consistency of test scores
- validity: the extent to which a test measures what it proposes to measure (Souza et al., 2017)
- sensitivity: the ability of a test to correctly identify patients with a disease. A test that is 100% sensitive means all diseased individuals are correctly identified as diseased, i.e., there are no false negatives (Swift et al., 2020)
- specificity: the ability of a test to correctly identify people without the disease. A test
 that is 100% specific means all healthy individuals are correctly identified as healthy,
 i.e., there are no false positives (ibid.).

Additionally, the review identified the following characteristics for each CAT:

- formats available for administration (paper, electronic etc.,)
- number of items and time taken to administer the test
- training requirements for administering the test
- licensing requirements (access and permission to translate and use in another language)
- licence costs

availability of a validated Welsh translation of the test.²

² i.e. translation followed internationally recognised (Wild et al 2005) steps for ensuring equivalence of meaning in Welsh and English.

Adopting a systematic approach, detailed information was collated from the websites of the licence-holders, where available. This was further supported by a review of each test using Google Scholar and examination of the grey literature. The Llais website confirmed the availability of the Welsh translations.

2.2. Method used for stakeholder engagement

The stakeholder engagement activities were undertaken between November 2021 and March 2023 and aimed to raise awareness about the research and develop a collaborative approach with MAS and other stakeholders.

Several public discussions, presentations and meetings to exchange knowledge were arranged among:

- professionals working in the field of dementia care
- people with experience of living with dementia and their carers
- the academic research community
- members of the public.

Activities included: an online webinar hosted by the Centre for Ageing and Dementia Research in January 2022;³ monthly Welsh Government dementia discussion groups; knowledge exchange meetings with Alzheimer's Cymru and other organisations; and presentations at events such as the National Eisteddfod and the Welsh Bilingualism and Dementia Resilience Sandpit Event.⁴ Information about the research was also published and disseminated in the Welsh language print media, social media and radio.

As a result of the engagement activities, around 30 stakeholders, including representatives from organisations such as Alzheimer's Society Cymru, Bangor University, and Public Health Wales, contributed to defining the scope of the stage one research and informed the recommended methodology for subsequent stages. See Annex 1 for the full list of stakeholders who contributed to this activity.

Draft research questions for dementia assessment practitioners, intended for use in subsequent stages of the research, were collaboratively produced with stakeholders and are shown in Annex 2.

2.3. Memory Assessment Services (MAS) network consultation

The MAS national network in Wales consists of 28 assessment clinics. Members of the research team attended two virtual MAS network meetings via Microsoft Teams in September and November 2022. During these meetings, the research aims and objectives were presented, along with the results of the desk-based review. Additionally, agreement

³ Attended by over 100 people with dementia care, experience of living with dementia and general interest backgrounds.

⁴ Full list of engagement activities with stakeholders can be found in the technical report, available on request from: research.healthandsocialservices@gov.wales

was sought to distribute a short online survey to MAS staff regarding their use of CATs. The online survey entitled Dementia a'r laith Gymraeg / Dementia and the Welsh Language is shown in Annex 3.

3. Findings

3.1. Findings from the desk-based review

Five sets of UK guidelines mention the use of CATs in different dementia care settings: Alzheimer's Society (2013), the Royal College of General Practitioners (RCGP, no date), NICE (2018), Public Health Wales (2021), and NICE (2021).

There are 13 CATs named in the five sets of UK guidelines⁵:

- Abbreviated Mental Test Score, AMTS
- General Practitioner Assessment of Cognition, GPCOG
- Mini Cognitive Assessment Instrument, Mini-Cog
- 10-Point Cognitive Screener, 10-CS
- 6-Item Screener, SIS
- 6-Item Cognitive Impairment Test, 6CIT
- Memory Impairment Screen, MIS
- Test Your Memory, TYM
- Informant Questionnaire on Cognitive Decline in the Elderly, IQCODE
- Mini Mental State Examination, MMSE
- Addenbrooke's Cognitive Examination-III, ACE-III
- Mini-Addenbrooke's Cognitive Examination, M-ACE
- Montreal Cognitive Assessment, MoCA

In addition to the CATs recommended in the UK guidelines, the Welsh Government requested the research team to explore the use of the CAT 'Repeatable Battery for the Assessment of Neuropsychological Status (RBANS)' because expert advice suggested that this scale was widely used across Wales at the time of commissioning.

The main findings from the review were:

 All CATs demonstrate established psychometric properties with good sensitivity and specificity⁶.

⁵ An overview of the tools recommended for use in every setting by each set of guidelines is provided in the Technical Report, available on request: research.healthandsocialservices@gov.wales

⁶ Please see Technical Report for more details: research.healthandsocialservices@gov.wales

- All CATs are easily accessible online via the publishers and permissible for administration
- All CATs are available in paper format, and five can be administered electronically.
- Except for the RBANS, which takes 30 minutes to administer, the administration time ranges from three to fifteen minutes.
- Licence costs are incurred with the use of the RBANS⁷ and MMSE⁸.
- Due to copyright issues, the MMSE is no longer recommended for use in the UK (Aziz and Ahmed, 2014). The MoCA, ACE-III, and 6CIT are cited as alternatives to MMSE (ibid).
- Since 2019, brief training and certification have become mandatory to administer and score the MoCA for clinical, research, and educational use (Nasreddine, 2019).
- Standardised Welsh translations for six of the CATs have been produced9.
- Except for the MMSE, the translation process adopted for establishing Welsh language versions of the CATs followed strict international guidelines (Wild et al., 2005) to ensure equivalence of meaning and linguistic validity.
- The UK Guidelines for using CATs in MAS recommend the use of only the ACE-III, MoCA, and MMSE.
- Due to costs, the MMSE is no longer feasible for NHS Wales (Aziz and Ahmed, 2014). The ACE-III and MoCA, however, are strong measures with valid and reliable psychometric properties for MAS. Both tests have been undergone standardised translation into Welsh, ensuring linguistic validity.

The attributes of the ACE-III and MoCA are detailed further in this section.

3.2. Overview of the Addenbrooke's Cognitive Examination-III (ACE-III)

The ACE-III (Mathuranath et al., 2000) is a cognitive screening tool recommended for use by health practitioners and researchers in patients over 50 years old with suspected dementia. It includes a battery of tests that assess five cognitive domains including attention, memory, verbal fluency, language and visuospatial abilities. The results are scored to give a total score out of 100. The score needs to be interpreted in the context of

⁷ Further information about the costs of the RBANS (Pearson Clinical)

⁸ The MMSE was originally distributed without cost. The current copyright holders, Psychological Assessment Resources 'will not grant permission to include or reproduce an entire test or scale in any publication (including dissertations and theses) or on any website' (Aziz and Ahmed, 2014). All users will need to purchase the tests (PAR).

⁹ Addenbrooke's Cognitive Examination-III (ACE-III); Mini-Addenbrooke's Cognitive Examination (Mini-ACE); Montreal Cognitive Assessment (MoCA); General Practitioner Assessment of Cognition (GPCOG); Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) and the Mini Mental State Examination (MMSE).

the patient's overall history and examination, but a score of 88 and above is considered normal; below 83 is abnormal; and between 83 and 87 is inconclusive. 10

Cognitive domains within the ACE-III have been validated against a battery of standardised neuropsychological tests (Mathuranath et al., 2000; Crawford et al., 2012; Hsieh et al., 2013) with high levels of correlation between the domain scores and targeted tests. Three different alternative versions exist (A, B and C), with different stimuli for the name and address recall to prevent recalling from the administration of previous tests. ¹¹ Both a paper and electronic version are available, and a training video may be accessed for administration purposes. The tool is freely available and permissible for administration.

The ACE-III has been translated into several languages and has been available in Welsh since 2014 and embedded in the Welsh language version of the Alzheimer's Society (2013) helping you to assess cognition: a practical toolkit for clinicians (Wales Mental Health in Primary Care). Since the publication of the Welsh translation of the test, the English (UK) version of the ACE-III has been updated to version 2017 (The University of Sydney). 12

Adopting a range of methodological approaches, normative values for different language versions of the ACE-III have been established in several countries. These take account of demographic influences such as age, education and sex. Using these demographically adjusted norms has been shown to improve the diagnostic accuracy of the ACE-III (Matías-Guiu et al., 2016). A comprehensive list of validation studies for the ACE-III, including those for its translated versions and normative data studies, is available in the technical report, upon request¹³.

The Mini-Addenbrooke's Cognitive Examination (Mini-ACE) was developed as a shorter version of the ACE-III. The Mini-ACE is designed for use in settings where administration of the full ACE-III is not practical. It assesses similar cognitive domains but in a more concise manner. The Mini-ACE has a total score of 30, with higher scores indicating better cognitive performance. The administration of the Mini-ACE takes approximately 5 minutes.

3.3. Overview of the Montreal Cognitive Assessment (MoCA)

The MoCA (Nasreddine et al., 2005) is a brief 30-point cognitive screening test designed to assist healthcare professionals in the detection of mild cognitive impairment. It sets out to assess seven cognitive domains including visuospatial ability, executive function, short-term memory, attention, language, concentration and orientation in time and place. The results are scored out of 30, with higher scores indicating better performance. Whilst a clinical assessment is necessary to interpret the results, a score of 18-25 is indicative of mild

¹⁰ Thresholds can vary slightly depending on the population being tested and the specific guidelines used by different practitioners

¹¹ It was not possible to ascertain whether all three versions of the ACE-III test are used in Wales from the desk research.

¹² The update involved minor clarification to one of the memory questions to resolve ambiguity: "Name of the woman who was prime minister" \rightarrow "Name of the first female prime minister.

¹³ research.healthandsocialservices@gov.wales

cognitive impairment; 10-17 moderate cognitive impairment and <10 severe cognitive impairment.¹⁴

The MoCA is reliable and valid (Nasreddine et al., 2005; Freitas et al., 2012; Koski 2013; Carson et al., 2018; Dautzenberg et al., 2020) and outperforms the MMSE in diagnosing mild cognitive impairment (Freitas et al., 2013). It can be used freely for clinical purposes but needs permission for research use. Certified clinicians or health professionals can administer and score MoCA, but only experts in cognitive fields should interpret results. Since September 2019, mandatory certification via a 1-hour online course ensures consistency, costing \$150 USD per person¹⁵ or free for students, faculty, and academic researchers with proper verification (Nasreddine 2019).

The MoCA has been translated into several languages. Version 7.1 has been available in Welsh since 2014 and embedded in the Welsh language version of the Alzheimer's Society (2013) 'helping you to assess cognition: a practical toolkit for clinicians' (Wales Mental Health in Primary Care). The English version of the MoCA was updated in 2017 to version 8.1 (MoCA Cognition).

Like the ACE-III, whilst adopting a range of methodological approaches, normative values for different language versions of the MoCA have been established in several countries. These also take account of demographic influences such as age, education and sex. Using these demographically adjusted norms has been shown to improve the diagnostic accuracy of the MoCA (Freitas et al 2013).

A comprehensive list of validation studies for the MoCA, including those for its translated versions and normative data studies, is available upon request in the technical report.

3.4. Desk-based review conclusion

Based on the desk review findings, the ACE-III and MoCA are the two CATs recommended for use in MAS in Wales. Both ACE-III and MoCA have been proven to be robust measures and a standardised, linguistically validated Welsh language translation of each tool has been available since 2014.

Nevertheless, there is a lack of information about the use of the Welsh language version of the ACE-III and MoCA in MAS settings in Wales and a lack of normative data to inform clinical practice.

3.5. Findings from the stakeholder engagement

MAS network survey: The survey was completed by 12 MAS¹⁶ representatives from five different health boards: Betsi Cadwalader, Hywel Dda, Swansea Bay, Cwm Taf Morgannwg and Powys university health boards.¹⁷ Eleven of the twelve survey respondents reported conducting cognitive assessments in a MAS. The ACE-III and Mini-ACE were identified as

¹⁴ Exact cutoffs can vary slightly depending on the source and clinical context.

¹⁵ Accurate at the time of writing

¹⁶ Breakdown of the number of responses from each health board is available in the technical report.

¹⁷ No responses were received from the Aneurin Bevan or Cardiff and Vale health boards

the most frequently used CATs for dementia assessment, while the MoCA was reportedly not widely used.

The ACE-III and Mini-ACE were reported to be used at least once a week or once a month in most of the MAS settings represented by the survey respondents. However, there was little awareness that there is a Welsh version of the ACE-III and Mini-ACE CATs.

Stakeholder engagement main findings: Stakeholders strongly supported validating Welsh language CATs for dementia diagnosis and further recommended that the ACE-III and Mini-ACE should be prioritised for validation in Welsh.¹⁸

Stakeholders noted the importance of defining 'bilingualism' for clinical assessments. Welsh-speaking patients who choose to be tested in Welsh are not necessarily monolingual. The validation of Welsh language CATs should consider the bilingual profile of patients and MAS staff. Testing in just one language can be problematic for those familiar with mixing both languages.

Stakeholders indicated what they believed to be the most appropriate research methods for further stages of validating Welsh language CATs. They considered semi-structured interviews with practitioners to be the most suitable approach for examining the practical use of CATs in MAS environments. Additionally, it was proposed to observe the administration of both the Welsh and English versions of the ACE-III and Mini-ACE with Welsh-speaking patients in MAS environments. This methodology was hypothesised to yield substantial data on bilingual practices in clinical settings, particularly regarding (i) the degree to which staff adhere to the More than Just Words Active Offer¹⁹ and the potential impact of staff practices on patients' choice to be tested in their stronger language, and (ii) the frequency with which Welsh-speaking patients provide monolingual or bilingual responses to CAT tasks presented in either Welsh or English.

Analysing this data will be essential for creating an appropriate research protocol for the psychometric validation of the ACE-III and Mini-ACE in Welsh.

When considering further stages of this research, stakeholders noted the importance of designing clinical data collection in partnership with MAS practitioners to ensure it integrates seamlessly into their everyday procedures. Ultimately, all seven university health boards in Wales should participate in the clinical study to standardise CATs for Welsh speakers across the region. However, a pilot study could initially be conducted within one health board to fine-tune the data collection approach. The anonymised CAT data collected should include fundamental demographic details such as age, education, gender, language profile, and diagnostic outcomes.

In addition, normative data from healthy Welsh-speaking populations should be collected, using similar demographic information available for people living with dementia. The sample should include Welsh speakers aged 50 and older from different parts of Wales to capture a

¹⁹ The Active Offer requires providers to offer services in Welsh proactively without the service user having to request them

¹⁸ While noting that these tests would benefit from psychometric validation with established normative values, they are not sufficient for testing all forms of dementia. Other forms of assessment will also be required.

range of accents, dialects, and experiences of using Welsh over their lifespans. The collection of normative data should be conducted by individuals trained in administering CATs.

The stakeholder group formed during stage one was deemed essential for the successful implementation of future community-based normative and MAS-based clinical research components, if such research is commissioned. This group should comprise individuals with lived experience of dementia as well as carers.

Finally, stakeholders noted the usefulness of developing comprehensive guidance for practitioners conducting assessments either fully or partially in Welsh.

4. Conclusions

The first stage of the research into the validation of Welsh language CATs examined the most frequently used CAT in MAS in Wales between the study period of 2021-2023. The results indicate that the ACE-III and Mini-ACE are the most frequently administered CATs in these settings. The review confirmed that the ACE-III and Mini-ACE are effective tools with the required psychometric properties and validated Welsh translations.

However, despite the availability of linguistically validated Welsh language versions of these tests since 2014, there is limited awareness and use of them among MAS practitioners. Additionally, there is a lack of normative data to guide clinical practice for the Welsh language versions of these tests.

The findings of stage one established the methodology requirements and set the foundation for subsequent stages of validation work. Future research should build upon these findings to ensure the development of robust, culturally, and linguistically appropriate CATs for Welsh-speaking individuals.²⁰

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²⁰ This research was qualitative in nature, and the small sample size urges caution in interpreting these results. Further stages of the research should revisit the conclusions drawn here before proceeding with additional work

5. Recommendations

Based on the findings of stage one, the following recommendations are made for the next stage of research:

Psychometric Validation: Prioritise the psychometric validation of the ACE-III and Mini-ACE in Welsh. This will ensure that these tests are reliable and valid for use with Welsh-speaking patients.

Interviews with Practitioners: Conduct semi-structured interviews with both Welsh-speaking and non-Welsh-speaking MAS practitioners to gather their views and experiences of administering the Welsh language version of the ACE-III and Mini-ACE. These interviews should aim to:

- establish the availability of training for those delivering the assessments
- assess any reported differences in the delivery of English and Welsh language assessments
- gather opinions on the communication of results within clinical teams, especially when not all members speak Welsh
- include stakeholders, such as clinicians, to discuss the use and interpretation of assessments in Welsh
- evaluate the availability of Welsh language assessments and Welsh-speaking assessors.

Field Observations: Conduct fieldwork to observe the cognitive testing of Welsh-speaking patients using both the Welsh and English versions of the ACE-III and Mini-ACE. This will help understand bilingualism in clinical settings and inform the development of a suitable research protocol for further validation.

Pilot Study for Clinical Data Collection: Conducting a pilot study of the ACE-III and Mini-ACE in a single health board is advisable to refine the cognitive assessment data collection for Welsh speakers. This pilot should be developed in collaboration with MAS practitioners to ensure it aligns smoothly with their daily workflows. The anonymised CAT data gathered should encompass demographic details such as age, education, gender, language profile, and diagnostic outcomes. The findings from this pilot will aid in optimising the data collection method prior to rolling out the study across all seven health boards in Wales.

Normative data collection: It is recommended to gather normative data from healthy Welsh-speaking populations. This data should include demographic details such as age, gender, education, and language profile, ensuring comparability to individuals living with dementia. The sample should consist of Welsh speakers aged 50 and above from various regions of Wales to capture a range of accents, dialects, and experiences with the Welsh language throughout their lives. This normative data collection should be conducted by researchers trained in administering the ACE-III and Mini-ACE assessments.

Ongoing stakeholder engagement: It is recommended to maintain the stakeholder contacts developed during the stage one research for the successful implementation of future community-based normative and MAS-based clinical research components. This group should include individuals with lived experience of dementia as well as carers.

Guidance for Practitioners: Develop guidance for practitioners undertaking assessments fully or partly in Welsh, informed by the findings of this and any stage two *research*, including input from linguistic experts. Make sure that the availability of linguistically validated Welsh language versions of CATs is widely recognised in MAS environments across Wales.

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Annex 1

Stakeholders who contributed to defining the scope of the stage one research and made recommendations for the methodology of further research:

Alzheimer's Society
Cymru
Bangor University
Betsi Cadwalader
University Health Board
Care Forum Wales
Carers Wales
Caron Group
Coleg Cymraeg
Cenedlaethol

Hywel Dda University
Health Board
IAITH
Individuals with
experience of living with
dementia or caring for
someone with dementia
Powys Teaching Health
Board
Public Health Wales
Royal College of General
Practitioners

Royal College of Nursing Wales
Royal College of
Psychiatrists
Social Care Wales
Swansea Bay University
Health Board
Together in Dementia
Everyday
Welsh Government
Welsh Language

Commissioner

Annex 2

Collaboratively produced draft questions for practitioner interviews suggested for subsequent Welsh language CATs validation phases:

- Do you speak Welsh?
- Would you prefer to complete this interview in Welsh or English?

General

- Do you work in MAS?
- What is your professional role?
- Do you assess patients for cognitive impairment?
- What MAS guidelines / protocols do you follow?
- What CATs do you use?
- Do you use the ACE-III and Mini-ACE? (and any other assessment tools?)
- If so, what is your experience of these tools?
- What training have you received in their administration?
- Do you use the paper or electronic formats?
- Where do you access these tools?
- What are the main advantages / challenges in using these tools?
- How do you record / document your findings? (In Welsh? In English? How do you share messages within the clinical team?)

Welsh language provision

- Do you see Welsh-speaking patients in your clinics? (Do you record the number of Welsh-speaking patients, and could that data be shared?)
- How and at what stage of referral do you know that they speak Welsh? (How do you know? What is your experience of Welsh and English? Is this question asked each time someone is assessed?)
- Are Welsh-speakers referred to Welsh-speaking practitioners in your clinics? (Is
 there someone in the clinic who can facilitate this e.g. colleagues from another
 area in Wales? How long do they have to wait? Is use made of simultaneous
 translation? If so, who provides the translation?)
- If so, is this a standard or ad-hoc procedure?

- In your opinion, what are the benefits / drawbacks in assessing Welsh-speaking patients in Welsh?
- Did you know that the ACE-III and Mini-ACE available in Welsh? (if know, know where to get them?)
- Do you or your colleagues make use of these Welsh language tools in your clinics?
- Do you have any opinions about their use?
- Do you use the paper formats?
- Where do you or your colleagues access these Welsh language tools?
- How do you record / document your findings?
- What are the main advantages / challenges in using these Welsh language tools?

Questions for Welsh-speaking practitioners

- How confident are you in assessing patients in Welsh?
- Do you use a translator?
- How supported by your organisation do you feel about using Welsh?
- What influences your use of Welsh in these circumstances?
- What procedures or protocols do you follow?
 - Respond to language choice / need for consultation?
 - Conduct consultation in English / Welsh / both languages?
 - Administer English ACE-III / Mini-ACE (with or without ad-hoc Welsh translation, as required)?
 - Administer Welsh ACE-III / Mini-ACE (with or without ad-hoc English translation as required)?
 - Allow for English and Welsh answers in scoring?
 - o Other?
- What is your experience of using the Welsh language versions of the ACE-II and Mini-ACE?
- What are the main challenges associated with administering these Welsh language tools?
- In your opinion, how may these challenges be overcome?

- There are no norms or normative data available yet on the Welsh language versions of the ACE-III and Mini-ACE. To what extent does this influence your practice?
- There are plans to collate these norms in a research project funded by the Welsh Government that sets out to recruit:
 - Welsh-speaking clinicians at memory clinics across Wales to collect anonymised data from a clinical cohort as part of their routine practice.
 - o Controls from community groups to mirror the clinical sample.
- What are your thoughts about this proposal?
- What challenges can you identify?
- Would you be interested in participating in the study?
 - o If yes, please provide your contact details.

Questions for non-Welsh-speaking practitioners

- There are no norms or normative data available yet on the Welsh language versions of the ACE-III and MoCA.
- However, there are plans to collate these norms in a research project funded by the Welsh Government that sets out to recruit:
 - Welsh-speaking clinicians at memory clinics across Wales to collect anonymised data from a clinical cohort as part of their routine practice.
 - o Controls from community groups to mirror the clinical sample.
- What are your thoughts about this proposal?
- What challenges can you identify?
- Use some of the questions asked above for those practitioners who use a translator to conduct the assessment

Additional Prompt Questions

- Why is that?
- Tell me more.
- Can you give me an example?

Do you have any other comments?

Annex 3

Online MAS consultation survey questions:

Dementia a'r iaith Gymraeg - Asesiad Dementia and the Welsh language - MAS Assessments

Diolch am ddilyn y linc, mae'r ffurflen hon yn gyfle i ni gasglu gwybodaeth am y asesiadau sydd yn cael eu defnyddio o fewn Rhwydwaith y gwasanaeth Clinig Cof. Bydd eich ymateb yn cael eu hanfon at Dr Catrin Hedd Jones, Prifysgol Bangor, a'i rannu gydag ymchwilwyr IAITH sydd yn arwain ar y gwaith ymchwil i ddilysu'r asesiad dementia Cymraeg a Rhwydwaith Gwasanaeth Asesiadau Cof.

Thank you for using the link, this form is your opportunity to share which Assessments are currently in use within Memory service teams. Your responses will be sent to Dr Catrin Hedd Jones, Bangor University, and shared with researchers at IAITH working for the Welsh Government and in partnership with the MAS network to gather knowledge on validating the Welsh language dementia assessments.

1.Wyt ti yn cynnal asesiadau yn y Clinig Cof? / Do you conduct Assessments in the Memory Clinic?

Yndw/ Yes

Na/ No

Byddaf yn y dyfodol/ Yes in the future

- 2.Beth yw teitl dy swydd a proffesiwn? Please tell us your job title and profession?
- 3.Ym mha Fwrdd lechyd rwyt yn gweithio? Which Health Board do you work in?

BIPBC / BCUHB

Hywel Dda

Bae Abertawe/ Swansea Bay

Cwm Taf Morganwg

Aneiryn Bevan

Powys

Caerdydd a'r Fro / Cardiff and Vale

4.Os wyt yn cynnal asesiadau hoffwn wybod pa brofion rwyt yn ddefnyddio o'r rhestr islaw / If you carry out assessments, we would like to know which ones you use and how often

Options: At least every week /At least once a month/ At least every six months /Never /There's a Welsh version of this test /I don't know this test

ACE-iii Mini -ACE RTI GPCOG MOHOST OSA AD8 The abbreviated mental test score (AMTS) Placemat Frontal Assessment Battery (FAB) MoCA OCAIRS EXIT 25 (Executive Interview) LACLs MMSE Mini-Cog 10-point Cognitive Screener (10- CS) MOHO Explore 6-CIT AusTOMs

5.Ydych chi yn defnyddio profion eraill yn rheolaidd sydd heb eu cynnwys yn y tabl?/ Do you routinely use any other assessments not listed above? Yndw/ Yes Na/ No

Os Yndw, beth ydi nhw? If Yes, what are they?

6.Sawl aelod o staff yn eich clinig sydd yn cynnal asesiadau? How many staff in your clinic conduct cognitive assessments?

7.Sawl asesydd ar hyn o bryd sydd yn siarad Cymraeg yn eich gwasanaeth?/ How many Welsh speaking assessors do you currently have in your service?

8.Beth ydi eich gallu Cymraeg? What is your current level of your Welsh?

Dim o gwbl / None whatsoever

Dangos cwrteisi, agor a chau sgwrs yn Gymraeg / Demonstrate courtesy, open or close a conversation in Welsh

Deall ac ymateb i geisiadau syml e.e. rhoi a derbyn cyfarwyddiadau / Understand and respond to simple requests e.g. give and receive instructions

Digon o eirfa i ddelio gyda sefyllfaoedd bob dydd, e.e. sgwrsio gyda rhywun dwi ddim yn adnabod / Enough vocabulary to be able to deal with everyday situations e.g. chatting to someone I don't know well

Trafod materion cyffredin a delio gyda sefyllfaoedd mwy ffurfiol os rwyf yn cael cyfle i baratoi e.e. cyfweliadau, cyfarfodydd / Discuss general matters and deal with more formal situations if I can prepare in advance e.g. interviews, meetings

Rhugl a medru delio gyda phob math o sefyllfaoedd / Fluent speaker and able to deal with every type of situation

9.Rydym yn gobeithio cydweithio â chi i sicrhau fod yr ymchwil yn llwyddiannus a defnyddiol i chi yn eich gwaith ac felly yn gofyn i unrhyw rai sydd â diddordeb yn y gwaith yma i anfon neges i XXXXXXXXX neu ffonio XXXXXXXXXX. / We would like to work with assessors to ensure that the research is planned in line with your processes and delivers useful results to facilitate your work. If you are interested in this research, please contact XXXXXXXX on email XXXXXXXXX or call XXXXXXXXXX to register your interest.

10.Unrhyw sylwadau hoffech ei rannu? / Any comments you would like to share with us? Yndw/ Yes Na/ No

11.Ydych chi eisiau i ymchwilwyr IAITH gadw mewn cysylltiad â chi wrth i'r ymchwil ddatblygu? / Would you like the IAITH researchers to keep in touch with you as the research develops?

Os felly , rhannwch eich manylion cyswllt islaw / If you responded yes to question 12 please share you contact details below