

Re-MEM: Developing Remote MEMory assessments

Background: The need for remote memory assessment

Diagnosing mild cognitive impairment (MCI) or dementia typically involves neuropsychological assessments, scans, physical examinations, and taking a medical history. Brief memory and thinking tests (such as the Montreal Cognitive Assessment) are often used in clinics to screen for objective memory impairment and to identify who may benefit from further assessment and treatment.

Modification of these tests allow clinicians to assess patients in their homes using a telephone or over the internet and are referred to as 'remote assessments'. Remote assessments can also be used in research to monitor cognition in research participants between study visits and may be useful in monitoring disease progression and treatment efficacy in clinical trials. Remote assessments are often bespoke to a particular study, though some tasks are more widely recognised (e.g., digit span).

Physically attending appointments can be difficult for some people and remote assessments offer greater convenience. Remote assessments which can be completed asynchronously (i.e., without being administered by a clinician or researcher) also mean that a larger number of people can be reached in a short amount of time compared to in-person or telephone/video-based assessments.

Re-MEM: a tool for remote verbal memory assessment

We have developed a prototype remote verbal memory assessment (Re-MEM) and worked alongside a patient and public involvement (PPI) group (N=12) to test the assessment and receive feedback from stakeholders (people with lived experience of MCI/dementia either as a person living with MCI or dementia or a carer/family member, people at risk of developing dementia (those aged >50), and individuals with professional interest in dementia). PPI meetings were conducted over Zoom at a time convenient for contributors both before trialling the Re-MEM task themselves at home (to learn about expectations of remote memory testing and prior experience) and shortly afterwards (to feedback on Re-MEM specifically).

We were particularly interested in:

- What are people's experiences with memory assessment and remote testing?
- What benefits could a remote memory assessment offer?
- What is important to consider when designing a remote memory assessment?

- What worked well and what could be improved?

This report summarises the learning and feedback from the PPI group.

What are people's experiences with memory assessment and remote testing?

Our PPI contributors had a **variety of experiences with memory assessment and remote testing** – from having never experienced any form of memory testing (in-person or remote) to currently being involved in a research study using remote cognitive assessments. Most contributors considered a memory assessment as something completed in a clinical setting using pen and paper, though this was associated with feeling like a 'test' and inducing performance anxiety. Completing an online verbal memory task could be made to feel more like a 'task' or 'game' – and there was some discussion about the **right terminology to use** (assessment/task/test) which might affect attitudes towards and experiences of completion.

The concept of a remote verbal memory assessment was considered **novel** - none of our participants had previously completed a remote verbal memory assessment and it was generally well-received as a **straightforward task with clear instructions and easy to complete in a short window of time**. Those who had completed online cognitive assessments previously referenced tasks/cognitive abilities such as [digit span](#) and [object/spatial recognition](#).

Generally, our participants were **familiar with using technology in their daily lives** and none of our PPI contributors reported feeling uncomfortable completing a remote memory assessment. When asked to consider how others less familiar with technology might experience the task (such as older relatives or those with dementia who did not regularly use technology), some participants expressed concerns that they may need help from others or may not be able to do the task or may not be willing to do the task. Several contributors expressed concerns about asking people who have not often used technology to do so for a memory assessment since this may affect their performance beyond their memory problems. It was generally agreed that those at-risk of memory problems or those with MCI would likely accept remote memory testing using an online platform.

What is most important to consider when developing a remote memory assessment?

Flexibility and choice were recurrent themes throughout PPI discussions, with PPI contributors highlighting that what works for some will not work for others. Several PPI contributors recommended giving people the choice between home vs. clinic, online vs. paper, and supported vs. unsupported tasks wherever possible, though recognised this may be difficult or not possible in a research setting.

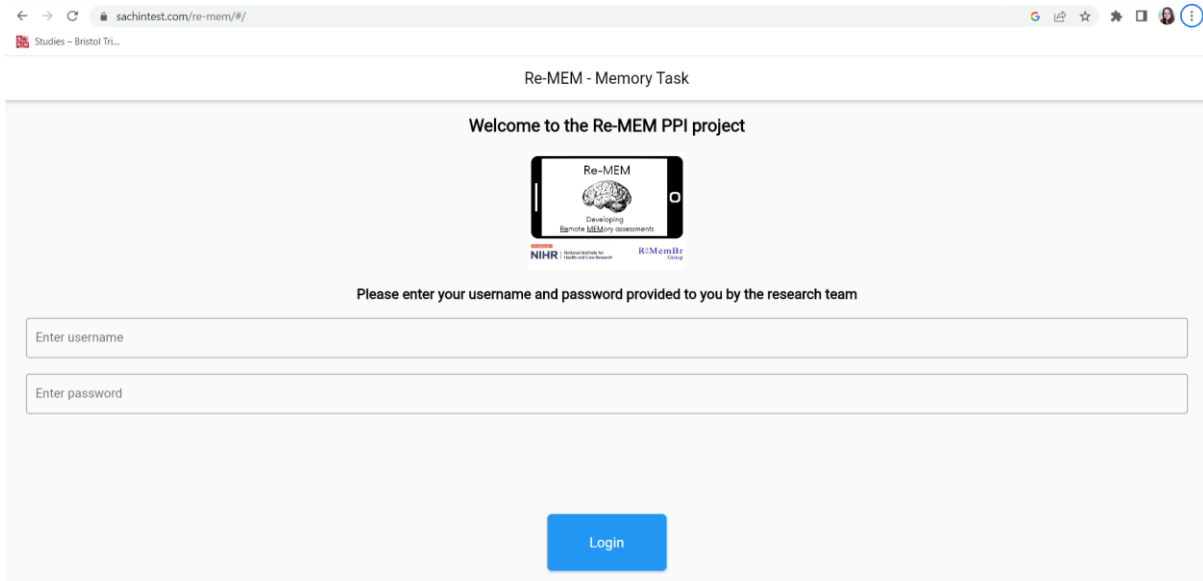


Timing was another key theme, with contributors highlighting issues with time windows for completing a task such as **routines, fatigue, chronotype** (morning vs. evening) and **sundowning** behaviours which may all impact concentration and memory. Asking participants to complete a task at their 'best' time of day for them (and perhaps even comparing it to their performance at their subjective worst time of day) was considered a good alternative. It was recognised that we would want to be as consistent as possible between individuals for scientific reasons, but that being too rigid might impede completion altogether.

Support from the clinical/research team and from family members was another recurrent theme. It was agreed that it would be beneficial to have some **guidance** for carers/family members on the kind of help that they could provide (e.g., technology assessment, reminders of the task) and what might impede an accurate assessment (e.g., prompting recall). There was discussion on what would be considered **appropriate help or support** after the assessment, with some contributors expecting (near) immediate feedback and/or reassurance, while others were happy to wait. Some felt that it would be necessary to offer support and resources to cope with anxiety around memory difficulties but others did not find the task distressing.

The Re-MEM task

Re-MEM is an online tool which enables a participant or patient to complete a memory assessment remotely at a time and in an environment which feels comfortable for them. It can be completed on any browser on any internet-capable smartphone, tablet, or PC and does not require any downloads or specific software, with login details provided by the clinician or researcher ahead of time to discourage completion by unintended recipients. The results are immediately available to the user (a researcher or clinical team) to download via .csv and can be used to generate summary scores and useful metrics for in-depth analysis of memory performance (e.g., reaction times, primacy effect, recency effects).



The screenshot shows a web browser window with the URL `sachintest.com/re-mem/#/`. The page title is "Re-MEM - Memory Task". The main content area has a heading "Welcome to the Re-MEM PPI project" and a central graphic of a smartphone displaying the Re-MEM app interface. Below the graphic, it says "Please enter your username and password provided to you by the research team". There are two input fields: "Enter username" and "Enter password". A blue "Login" button is positioned below the fields.

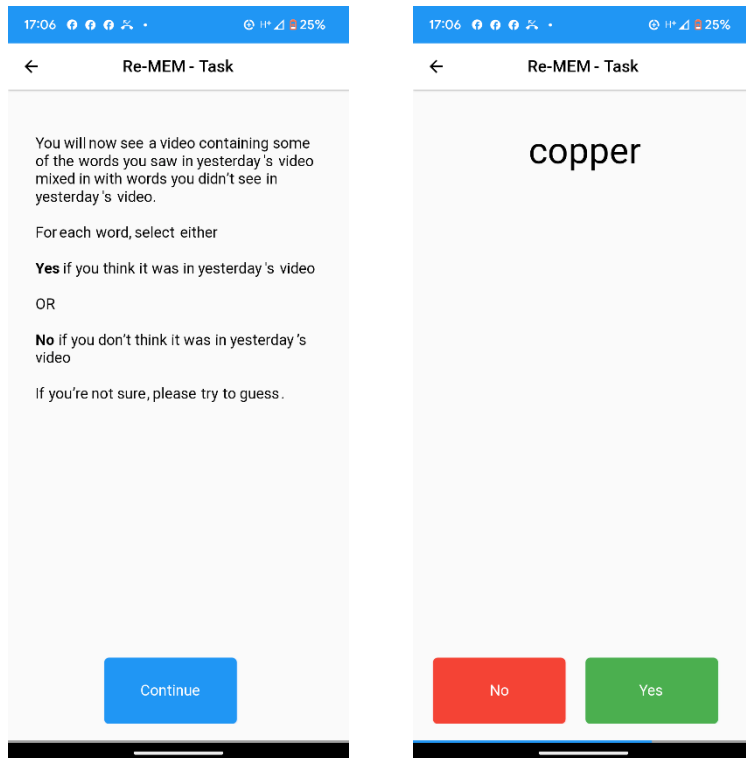
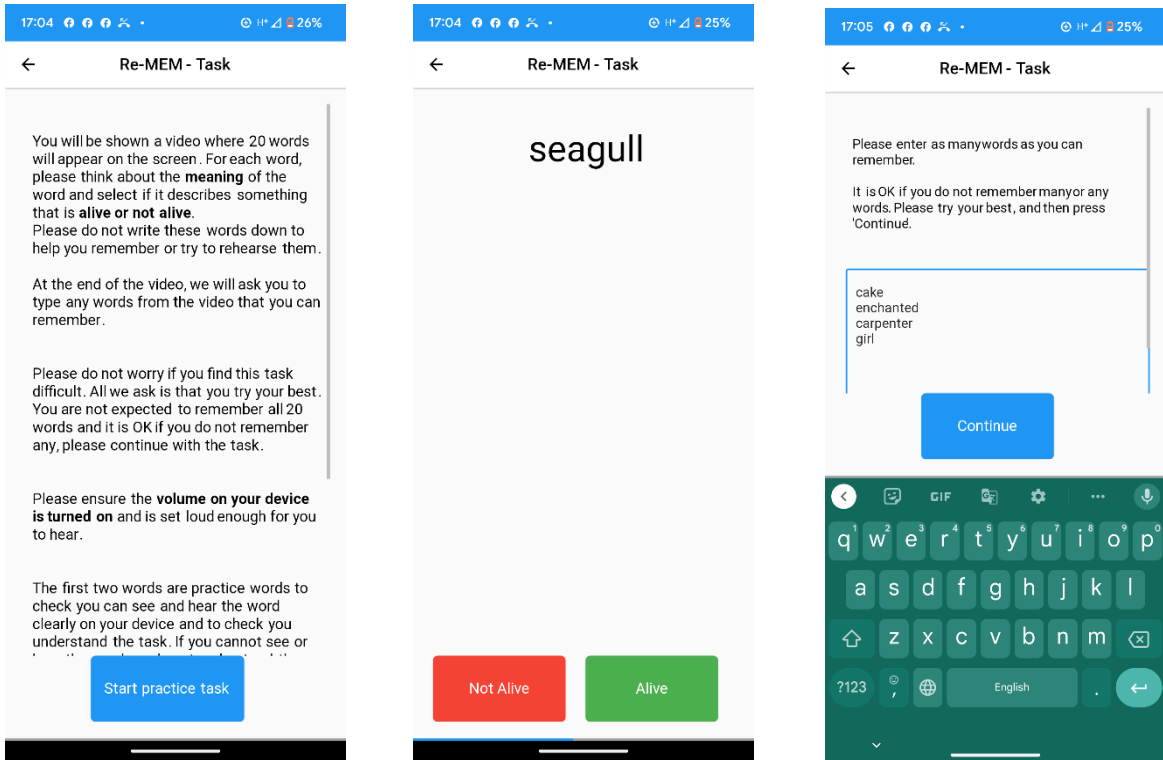
Re-MEM involves three tasks:

1. **Learning and immediate recall:** the participant is exposed to a list of words and asked to decide if they describe something that is "alive" or "not alive". At the end of the list, participants are asked to enter any words from the list they can remember, without any cues given (immediate free recall). The same list is then shown a second time.
2. **Delayed recall:** after a given time delay and without cues, the participant is asked to recall any words they can remember.
3. **Target-distractor recognition:** Participants are shown a list of words containing the words they saw yesterday (targets) mixed in with words that they did not see (distractors) and are asked to select 'yes' if they recall seeing the word in the original list shown.

The modular design of the Re-MEM task offers **flexibility** for users to decide the delay between exposure and testing. Users would also be able to amend the difficulty of the task through changing the number of exposures to each target word or changing the number of target words. Word list learning tasks are often used to measure verbal episodic memory in



MCI and dementia research (ref). Combining immediate and delayed free recall with delayed recognition memory may have added benefit in understanding prognosis (ref) or staging.



Feedback from PPI contributors following Re-MEM completion

Benefits of Re-MEM

- **Convenience** – timing, location, brief task to complete, did not need to travel into a clinic or research facility or pre-agree a time with a researcher to complete.
- Feel more **comfortable and natural** in the home environment – one participant mentioned how her mother with dementia performed much better at home than in an unfamiliar place in neuropsychological testing (likely due to stress of an unfamiliar place and tester, as well as the stress of attending a visit).
- **Concentration** – able to concentrate better, feeling less ‘flustered’ or pressured than in a clinic.
- Could help form ‘clinical picture’ alongside other information (GP referral) so may help with triaging memory clinic patients ahead of first clinic visit.
- **Avoiding travel** considered a major benefit – the stress and expense of getting to a clinic appointment may really impact someone’s cognitive performance and there is an environmental benefit too if it saves a clinic/research appointment visit.

Problems with current iteration of Re-MEM

Re-MEM **focuses on verbal memory**, whilst several PPI contributors highlighted that assessing different forms of memory (e.g., digit span, object recognition) would give a **more comprehensive assessment** and be more **inclusive** (e.g., for people with dyslexia, non-native speakers). These concerns could not be addressed within the timeframe or budget for Re-MEM, but further development will explore how to make the task more inclusive, including voice-to-text functionality for people with visual impairments or dyslexia.

Digital literacy and digital poverty: The participants we had in the PPI testing group all had Wi-Fi and capable devices, which was necessary for participation in the PPI group. However, some participants who had recently cared for parents with dementia discussed how their parents would not have been able to use technology and would have needed a lot of support to complete any internet-based activities. One contributor offered the example of her mother who had early visual problems and used to get confused using a mobile phone. We would need to consider an alternative for those unable to use their own device (e.g., loaning a device or coming into a clinic or GP surgery) and those who do not want or are not able to complete using technology for any reason (e.g., a phone call).

Guidance for carers/family members was requested to recognise and support those who may be assisting the participant to complete the memory task on what is an appropriate amount of support.

There was also **recommendations for additional features to support engagement and reduce anxiety**, specifically:

1. **Prompt to move on to the next task** when there has been a significant delay without response (e.g., "Would you like to move on to the next task?") so they don't spend too much time and expect to have to remember every word.
2. **Markers of progress and encouragement** during the task (e.g., "You're nearly there" or "Well done, keep going!") which do not comment on how well the person is doing on the task. During the test words, it might be good to say 'Well done', or 'Let's try that again' to show that responses were acknowledged.
3. There should ideally be a way to immediately and securely **reset the login details** instead of waiting for someone to be available to do this manually.
4. **A reminder sent near the end of the window** would be helpful to reduce missing data. Participants were asked to complete the task within a given time window (in the evening and following morning), so reminders in the last hour or after the evening task might be beneficial.

Some technical issues were identified which need addressing in future iterations:

1. **Confirmation of response recorded:** The response buttons did not give any indication if they had been successfully pressed. Some visual cue is needed (e.g., indentation, change in colour, bold, highlighted) otherwise participants kept pressing and weren't sure if their responses were recorded, which was distracting.
2. **Excessive delay:** The delay between words presented was considered excessive for assessing those with no to mild/moderate memory problems and could be distracting from the task as well as frustrating. A briefer timeframe was requested.
3. **Problems with completing on a mobile:** It is difficult to see the actual typing on a smartphone when the keyboard pops up. It is also easy to select the wrong answer since the screen is small. This might be particularly problematic for anyone with larger hands, or with tremor or poor dexterity. There were also concerns about using a smartphone for this task, due to the increased likelihood of unwanted notifications from other apps or calls which could either distract or otherwise interfere with the task. It might be worth seeing if we could temporarily pause notifications on the device (e.g., similar to PowerPoint in 'full-screen' presenter mode).

General feedback on the Re-MEM task

Timing of Re-MEM (mixed feedback)

We originally asked participants to complete Re-MEM in a specific time window during the evening and following morning but adapted this to a longer window respective to waking hours (i.e., within 5 hours before bedtime and within 5 hours of waking). However, some



participants reported that their cognition was worse in the morning and evening due to feeling groggy, whilst others said this schedule didn't fit with their routine. Others mentioned sundowning as a concern, and that it may be difficult for people with dementia to complete a learning task in the evening or first thing in the morning. A suggestion well-received was to ask participants to complete on 2 consecutive days but at a time of day that they felt able to concentrate well (e.g., matching their chronotype). Others said that not having a specific time window to complete the task meant that they would likely forget, so were happy with the suggested time windows. It was also discussed how struggling in the morning and evening might indicate sleep/functional issues.

'Alive or not', categorisation task (largely positive)

The 'alive or not alive' categorization element of the task was well-received and considered to add interest to the memory task, though participants disagreed on the definition of 'alive or not alive'. It might therefore be worth adding at the de-brief that people may have alternative definitions for 'alive' but all are valid. There were also some ambiguous words which sparked discussion. A minority of participants would have preferred unambiguous nouns (clearly alive or not alive) or a different categorisation task. Participants seemed engaged with the task.

Ease of completing task (positive)

Participants reported finding it easy to find a space (at home) to complete the task in comfort and free from distractions. Participants with MCI reported that the task was challenging for them, but that they understood the task and enjoyed its 'simplicity'.

Several participants referenced other cognitive-related tasks, such as crosswords or puzzles, as something they enjoyed and also suggested that this may confer an advantage compared to people who do not usually enjoy such challenges.

The PPI contributors suggested that a digital remote memory test would be well-received by people who already use technology for other tasks. However, a significant proportion of older adults are not comfortable with, or do not have access to, the internet and smart devices. If Re-MEM were implemented, it would be important to have an alternative form of the test (e.g., telephone or researcher present, or support at the clinic appointment to complete).

It was generally agreed that most people would prefer a link to an internet browser-based task rather than a smartphone application which needs to be downloaded.

Changes made to Re-MEM based on feedback

In the first iteration of Re-MEM, once the user had selected 'alive or not alive' against a word, the task would move immediately on to the next word. This meant that the faster a



participant responded the less exposure they had to the word. In the next iteration, the word remained onscreen for 8 seconds even if a response was selected. Feedback suggests this pause was probably too long and could be comfortably halved but did allow the participants to spend longer thinking about the target words. We also added in a “progress bar” along the bottom which shows the participants’ progress in the task following previous feedback that this might be helpful. This was well-received by our current participants who felt reassured that they were progressing through the task and that their responses were being logged.

Considerations for future development of Re-MEM

Participants with MCI reported that having **something personal** within the task, such as entering a name or year of birth, might help someone to feel more comfortable, since they are being asked to use something that they are concerned about losing, and may find this process (being able to recall something correctly) **identity-affirming or reassuring**. This could also help to verify that the person using the login is the **intended recipient**.

It might be worth adding some additional questions to the Re-MEM task that could assist with **screening for memory problems** (e.g., about if they have subjective memory complaints, if there were distractions during the task, or how comfortable they are with technology). One contributor suggested asking participants if they had any **examples of a recent memory lapse** or something specific that they were concerned about regarding their memory (e.g., forgetting life events vs. forgetting if they locked the garage door).

Participants reported that completing the Re-MEM task felt **brief**, and that they would not mind doing additional cognitive tasks either before or afterwards (e.g., story-based memory, visuospatial tasks). Re-MEM could be developed as a comprehensive, brief memory assessment similar to a MoCA, and delivered without a clinician present.

Following feedback on negative associations with the colour red, the response buttons could be changed to blue and orange.

Interesting feedback that could be otherwise useful

- **Strategy:** one participant (with MCI) reported trying to make a link between several words to try to remember and recall them, but that this actually impeded his memory as he recalled a related non-target word. The same participant used the alphabet to try to improve recall. A different participant with MCI recalled looking around the room to see if there were related items that triggered recall and said that relevant



words to recent events were easiest to recall. One participant actively tried not to look around the room for triggers.

- **Visual impairment/changes in dementia:** One participant described how her mother with dementia struggled to recognise an object even in the earlier stages of dementia, and she would get confused with mobile phones in particular.
- **Agreement that friend/family member feedback could be really useful** both for research and at the stage of diagnosis/screening. Friends/family members might notice changes that the person themselves either doesn't notice, or does not want to admit – subtle but noticeable differences that might help with contextualising behaviours. One example given was of a relative with dementia who was able to completely mask their symptoms when a community nurse visited for an assessment, but then broke things and became angry and upset and returned to their usual symptoms, after the nurse left. If relying solely on the patient's point of view, this might have been misleading. Similarly, symptoms may be intermittent especially at the earliest stages so may not be picked up in a formal assessment.