NHS

Yorkshire and the Humber
Clinical Networks

Memory Service Assessments: A New Way Of Working

NHS England and NHS Improvement

Memory Service Assessments: A New Way Of Working

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Prepared by: The group that developed this report is listed in Appendix 1 - we look forward to any comments on the proposals to Alistair.Burns@manchester.ac.uk.

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1. Background

The COVID-19 pandemic has inevitably led to changes in the way Memory Assessment Services (MAS) operate. Anecdotally, these have varied across the country. Some MAS staff have been redeployed to other activities within mental health trusts, some services have closed to new referrals and some clinics have put on hold new assessments on people who had been already referred. At the same time changes in primary care in terms of working online and modification in referral behaviour, means that there may be longer waiting lists and when services do re-open, delays in obtaining appropriate support for people who have memory problems and dementia.

Other services are continuing to accept referrals and have embraced alternative ways of working such as using telephone or video consultations to assess patients, perform neuropsychological testing, change thresholds for investigations like brain scans and share diagnoses. While some assessment may be better than none, these new working practices have raised concerns about the potential for alternative assessments to lead to lower quality assessment and care through incorrect or incomplete diagnosis, suboptimal management decisions and weaker support after diagnosis.

This short paper results from a virtual meeting of a multidisciplinary group of memory assessment specialists and GPs (see Appendix 1). Although our focus is on best practice during the COVID-19 pandemic, we hope that the legacy will include improved access to memory services and support in years to come.

2. General Principles

The group strongly supported the overarching principle that the quality of the diagnostic process and the way in which the diagnosis is shared is paramount and should not be undermined. The group further articulated three core principles which should underpin any change in the way services are configured and carry out their activities.

2.3 The service should be needs led

The current pandemic and social distancing have changed the way that people are presenting for assessment, diagnosis and support. When fear of catching COVID-19 was intense, many people (the majority of whom are elderly) did not wish to come to hospital for an assessment and often did not present to their GP with concerns. A drop in the national dementia diagnosis rate reflects this and is in keeping with other specialty areas where demand for non-COVID services has reduced significantly. People with undiagnosed dementia might still come to medical attention through presentation with an acute problem such as delirium, agitation or distressed behaviour. However, as the NHS returns to normal the number of people concerned about the possibility of dementia and seeking assessment will rise. As we emerge from the COVID-19 pandemic, the capacity of MAS must be sufficient to meet (and be responsive to) the needs of people referred for assessment.

2.4 There should be equality of access

Many of the adaptations to MAS that remained operational during the pandemic have relied on remote consultations. Changing to remote consultations carries the risk that some patient groups become marginalised, by not having access to a particular technology or have other reasons that undermine the technology’s efficacy. For example, some patients or carers may lack the necessary facilities for videoconferencing (e.g. computer, webcam, broadband and experience in using them) or have particular disabilities (e.g. deafness, speech difficulties) that make remote consultation challenging or lack the home space necessary to have a private conversation.

Similarly, while remote consultations with people for whom English is not their first language can be conducted via an interpreter, additional time must be set aside for translation. Together, these problems prevent a seamless and meaningful assessment for a significant minority. While many older people are comfortable using technology, some are not, and it is likely that these difficulties are associated with other well-established barriers to healthcare associated with race, poverty, disability and locality. New working practices must aim to overcome rather than exacerbate health inequalities (https://www.ethnicity-facts-figures.service.gov.uk/culture-and-community/digital/internet-use/latest#by-ethnicity)

2.5 Risk should be assessed and monitored

There are potential risks associated with any rapid change in working practices. The risk that many a thoughtful clinician fears is misdiagnosis of a treatable cause of cognitive impairment. In particular, the risks and benefits of a having a hospital-based brain scan (even as an outpatient) as part of the diagnostic process needs to be considered. There is also an important risk that the diagnosis of dementia may be missed because of insensitivity of remote assessments, with consequent harm through missed treatment and support for people with dementia.

Other risks include missing treatable symptoms and signs because they cannot be adequately assessed without a physical examination (e.g. cardiac arrhythmia, hyper/hypotension, parkinsonism, postural stability); a lack of privacy preventing open dialogue (e.g. on mood, psychosis, suicidality); risks caused as a direct result of the dementia; and the risks resulting from the added difficulty in establishing a good rapport on which basis to engage, inform, and reassure patients or families. The thrust of newly configured MAS practices should be not to avoid risks altogether or push the risk onto patients, but to recognise the risks, be honest and transparent with patients and their families about the risks and take steps to mitigate their effects. Clinical training and supervision are key components. The GMC has published guidance on remote consultation (https://www.gmc-uk.org/ethical-guidance/ethical-hub/remote-consultations), as has NHSX (https://www.nhsx.nhs.uk/covid-19-response/data-and-information-governance/information-governance/).

3. Components of the Diagnostic Pathway

3.1 History

The history of the presenting complaint with collateral information from the family is probably as easy to gather on the telephone for most patients as it is face to face (exceptions include deafness, aphasia and the need for an interpreter). Issues of consent to contact relatives may arise (taking into account any urgent safeguarding concerns) and this may be more complicated by telephone compared to an assessment where both attend a clinic or are visited at home. Where possible, having relatives in one place is convenient provided physical distancing rules can be maintained, and as long as time and space is made for individuals to speak confidentially, without being overheard. These issues are similar to the management of interviews when family and relatives attend an outpatient appointment together. It may be that some advance notice of the questions might be appropriate.

The IQ CODE (https://www.cochrane.org/CD011333/DEMENTIA_using-structured-questionnaire-iqcode-detect-individuals-who-may-go-develop-dementia) is a helpful instrument of proven validity which allows the family and person to detail the onset and progression of symptoms. However, the use of this single instrument is no substitute for taking a thorough informant history with a broad enquiry into the course and content of symptoms and other illness. It was felt by the group that emphasising the paramount role of a thorough and well-informed individual and informant history in the diagnosis of dementia was important – rather than overreliance on cognitive test scores or brain scans.

3.2 Cognitive Assessments

There are about 20 telephone based assessments of cognition available, most of which have been validated (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3933813/). Some are adapted variants of commonly used favourites such as the Mini Mental State Examination (MMSE) and the Montreal Cognitive Assessment (MOCA, https://www.mocatest.org/remote-moca-testing/ and some specifically developed or adapted for use on the telephone (e.g. the Telephone Interview for Cognitive Status, TICS, and the modified version, TICSM) which correlates with the MMSE (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2783323/). Many are subject to copyright restrictions https://www.parinc.com/products/pkey/445). NICE has outlined the tests for which there is an evidence base (https://www.nice.org.uk/guidance/ng97 pages 50-52).

The Test Your Memory (TYM) was widely discussed and has been validated against a number of measures http://www.tymtest.com/. The main TYM tests http://www.tymtest.com/ are designed to be completed by patients under supervision, although not necessarily a health professional and can be completed via telephone (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6787922/). The Free Cog (https://www.ncbi.nlm.nih.gov/pubmed/31315124) is a new instrument which combines assessment of cognitive and executive functions which may be useful and can be adapted to be given over the telephone (information available from Alistair.Burns@manchester.ac.uk

In primary care, brief tests to detect cognitive impairment are available and many are feasible over the telephone. For example, the GP Cog (http://gpcog.com.au/) could easily be carried out on the telephone with the omission of the clock drawing test. The 6 item CIT (https://patient.info/doctor/six-item-cognitive-impairment-test-6cit) can be given on the telephone. Further advice on the range of test available is available at https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/alzheimers_society_cognitive_assessment_toolkit.pdf.

Where a video consultation is feasible, it is often easier to negotiate a more traditional test such as the Addenbrooke's Cognitive Examination (ACE), MOCA (https://www.mocatest.org/remote-moca-testing/) or MMSE. Many parts of the ACE can be administered remotely, and with a bit of planning even the language and visuospatial elements can be completed. Screen sharing functionality on systems such as Attend Anywhere (https://www.attendanywhere.org.uk/) can support this. A remote version of the ACE is available. While these tests have not been explicitly designed for this purpose, there is a need to be pragmatic. Clinicians will need to gain adequate practice in the remote administration of them prior to use even if highly familiar in their traditional administration, with due caution in their interpretation.

None of these tests are diagnostic, so none make the diagnosis of dementia, they simply measure cognitive function, and all are subject to error such as by sensory impairment, educational level, and culture or language. The group emphasised that assessment on a cognitive test is more than simply administering the test and much information can be gathered during the assessment which adds qualitatively to the numerical value given. The nuances of this will be lost on the telephone and may be less easy to detect on a remote video assessment. It is as important that a clinician uses an instrument with which he or she is familiar, and whose limitations they understand, while recognising the potential value in flexible approaches (e.g. supplementary questions to elicit cognitive impairments or using nhs.net email for carers to send a smart-phone picture of the clock drawing test during a telephone assessment).

3.3 Formal Neuropsychological Testing

The British Psychological Society (BPS) Division of Neuropsychology (DoN) has recently released guidance regarding the remote administration of neuropsychological assessments (Professional Standards Unit, DoN, 2020, https://www.bps.org.uk/member-microsites/division-neuropsychology). The need for a careful consideration of the risks and benefits of remote neuropsychological assessment is pivotal. There are significant advantages to conducting neuropsychological assessment by video conferencing rather than telephone, given the greater comparability to face-to-face interaction.

Particular attention needs to be given to clinician familiarity with the remote administration of the test, training, practice, and the patient's ability and willingness to engage in remote assessment, to enable effective assessment and interpretation of test results. There is an encouraging evidence base indicating that valid results can be achieved by remote administration of neuropsychological tests (eg the Repeatable Battery for Assessment of Neuropsychological Status, RBANS, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4718188/). As neuropsychological expertise is often offered to people with complex presentations, (particularly subtle cognitive changes or visuospatial difficulties), these profiles may be more difficult to delineate by remote testing.

For people who are not able to undertake formal assessment at present, a thorough neuropsychological clinical interview by telephone with the patient and informant may be both acceptable and beneficial to starting the assessment process and clinical decision-making.

3.4 Brain Scanning

It is likely that brain scans will be requested less frequently at present, both because of reduced radiology services and because patients and families may not want to put themselves at risk by coming to hospital. If there are COVID and non-COVID areas of healthcare facilities, this may become easier.

A discussion should be undertaken with the patient and the family about the risks and benefits of having a scan, whether it is urgent or can be deferred, and the likelihood that the result will change a management plan. If the patient has had a brain scan within the life time of the cognitive symptoms this could be sourced and re-reported (if required).

Guidance has been developed which offer advice on clinical situations where a scan may or may not be necessary. For example:
http://www.yhscn.nhs.uk/media/PDFs/mhdn/Dementia/Dementia%20Diagnosis/Neuroimaging%20guidance/Yorkshire%20and%20Humber%20Neuroimaging%20Guidance%20in%20Dementia%202018.pdf
https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2019/09/Neuroimaging-for-dementia-diagnosis-London-Dementia-Clinical-Network.pdf

3.5 Blood tests

These would be organised, as per usual practice, in Primary Care. There should be flexibility in the time between the blood test and the assessment rather than the standard six months rule. Blood tests performed during the lifetime of the cognitive symptoms may be considered acceptable. In patients without prior blood tests, consideration of whether to request these during the pandemic should be assessed on a case by case basis. Unless there is a clear clinical indication, waiting for blood tests should not hold up the diagnostic and treatment processes, provided that the possible differentials to the ‘working diagnosis’ are not forgotten.

3.6 Other aids to diagnosis

- Diadem is a validated brief tool which is of value in helping to diagnose advanced dementia in care homes.

  http://www.yhscn.nhs.uk/media/PDFs/mhdn/Dementia/Dementia%20Diagnosis/2016/DiADeM/DiADeM%20Tool%20Final%2002092016.pdf

- The Wessex dementia toolkit supports the assessment process and aids the diagnostic process. https://tinyurl.com/WessexDemToolkit

- Online and computerized cognitive testing is also available (see appendix 2). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6787729/

4. Peri-diagnostic and Post-diagnostic Support

The importance to patient and carer of sympathetically conveying the diagnosis and providing time for discussion of its implications and management cannot be overestimated. Many treatments can be initiated with advantage even during the period of restricted assessments. For example, initiation of cholinesterase inhibitors (CEI) is possible in the majority of patients without the need for an ECG. Anecdotally, in the absence of a history of cardiac problems and related symptoms, asking a relative to take the person's pulse is a good proxy but the safety of this approach has not been formally assessed and some relatives may not be willing or able to do this. Health care professionals visiting the patient for an unrelated reason may be able to check a pulse rate.

Advice on indications for carrying out an ECG is available here: http://www.yhscn.nhs.uk/media/PDFs/mhdn/Dementia/ECG%20Documents/ACHEIGuidance%20V1Final.pdf. Prescribing memantine might be more straightforward than initiating a CEI if there is a recent e-GFR, while noting the difference in indications.

Other treatment options remain entirely feasible. Treatment of depression and anxiety can alleviate memory symptoms. Access to non-drug treatments via IAPT has been affected by the pandemic, although there are some useful internet-based alternative resources, and the relative role of drugs vs IAPT may be changed temporarily. The reduction of vascular risk can begin even during the pandemic restrictions, with longer term follow-up and consolidation, along with raised awareness of other co-morbidities and detrimental effects of polypharmacy. Treatment of sleep disorders (including sleep apnoea) may need to be deferred. However, reducing polypharmacy and anti-cholinergic burden can often be safely initiated after a remote assessment.

Communicating the diagnosis of dementia to the patient and to their family and doing so in a way that is sensitive, informative and constructive is a fundamental element of MAS. Remotely giving information, education and reassurance is more difficult than discussing medical treatment options. The point where the diagnosis of dementia is communicated is critical for the health and wellbeing of people with dementia and their families. MAS need to generate a process to ensure that this is done well and that all information is communicated in a way that can be understood and that all questions can be addressed. It is likely that this well take more than one telephone call and separate calls may need to be held with the person with dementia and family carers. It will not be enough to direct patients and families to existing internet resources, though in many cases these resources may be helpful.

Particular care is needed to support and inform those families who lack the facilities or confidence to draw on internet resources, including minimising the risks of misinformation. Dementia advisors have a crucial role to play following diagnosis or, if the diagnostic process is taking longer than usual, supporting people and giving advice during this period. There should be a management plan for identified risks and agreements made about referrals to other services such as the Community Mental Health Team or social services as appropriate.

Due to anxieties surrounding COVID-19 and the closure of day centres and respite facilities, support for carers is more important than ever. NICE recommends that carers should be offered a psychoeducation and skills training programme. Strategies for Relatives Intervention (START) can be delivered via a telephone or video consultation (https://toolkit.modem-dementia.org.uk/wp-content/uploads/2016/03/START-Intervention-Summary.pdf). Group Cognitive Stimulation Therapy (CST) is recommended for people with mild to moderate dementia and is available in many memory services. In the current situation, individual CST via manual based activities with the family carer can be useful (cstdementia.com). Memory services are also developing novel ways to deliver CST using activity packs by post supported by individual CST by phone, or by CST groups via remote consultation.

5. Technology and Confidentiality

Ownership and ability to use a telephone, landline or mobile, usually with a speakerphone is widespread in the UK. Experience shows that these contacts are usually well received by patients and their families who appreciate the need to avoid an unnecessary hospital visit, and value an early assessment. Video consultations require more preparation and raise privacy concerns.

Privacy at the patient end may be difficult, although at the very least the healthcare assessor should determine who is present with the patient and whether the conversation is private, shared on a loud-speaker, or in a multi-occupancy dwelling (https://www.gmc-uk.org/ethical-guidance/ethical-hub/remote-consultations).

Privacy at the healthcare end of the call is also essential. Several proprietary systems of sufficient security are available including NHS recognised services for consultation and MDTs (e.g. Attend Anywhere - other providers may become available).

In many of the systems available, especially those sanctioned by the NHS, confidentiality of the connection is a given. However, conducting calls in a private office (even if working from home), is essential, exactly as in an outpatient clinic. It may be that, with appropriate consent, three-way consultations between the patient/partner/carer, GP and consultant would be helpful.

6. Case Studies

To illustrate the new working practices, we offer three illustrative assessments as summarised in the accompanying diagram (see Appendix 3).

Case 1

Mrs Smith is a 62 year-old lawyer who for the past three months, has felt more anxious. She says that she has always been a worrier and has found the changes as part of the COVID pandemic to be particularly stressful. Her husband has rheumatoid arthritis and diabetes so is in the shielded group. This has meant that she has had to work from home. A few weeks ago, she was told that her contract might not be renewed because of a downturn of activity in her legal firm. She says she has begun to forget day-to-day things and often goes upstairs to a room and forgets why she has gone there. Her mother died two years ago of Alzheimer’s disease.

She is generally fit and healthy and is managing around the house. With her permission, you have a brief discussion with her husband who corroborates the history. She has access to a laptop with a camera at home and so a remote video consultation is feasible. She scores 95/100 on the Addenbrookes Cognitive Examination (adapted to be delivered remotely).

You discuss with her that a diagnosis of dementia is unlikely and that her family history doesn’t put her at increased risk. She is reassured by this. You refer her to IAPT and say that if she is still worried in six months times to come back. You also provide some online resources for her about memory training.

Case 2

Mrs Patel is aged 83. There is a three to four-year history of slowly progressive memory loss since her husband died, particularly over the last six months, prompting her to move in with her son and his family. The family have noticed her to have difficulties organising the new software package her children installed which allows her to see her grandchildren in Australia. She used to be the family cook but now has difficulty organising and making a meal. She has begun to get up at night and has wandered into other people’s bedrooms. She has lost some weight over the last six months. She had a health check four months ago and all her blood tests were normal other than a slight anaemia which the GP treated with iron tablets.

You interview Mrs Patel on the telephone. She was disorientated to time, had no knowledge of current events, and did not know what the current isolation arrangements were for. She could not complete a test of attention. A detailed formal cognitive test was not practical during the phone call (although consider the options for easy-to-apply remote cognitive tests for future clinics, as above).

You discuss the situation with Mrs Patel and with her son and daughter-in-law who join by speakerphone. You think that the most likely diagnosis is one of a dementia. It comes as a shock but not a surprise. You offer a brain scan but the family say they would rather that she did have one at the moment because of the risks of going to the hospital. You explain the chance of finding an alternative and treatable cause is low but you would keep that under review. You involve the local dementia advisor and say you will phone them in six weeks to see how they are getting on and to discuss the possibility of starting medication.

Case 3

Mr Jones is a 56 year-old man with a three month history of difficulties with memory. His wife has noticed that he has great trouble parking the car and when he was recently reversing out of a parking space, did not seem to be able to judge which way to turn the steering wheel. He has worked as an electrical engineer for many years but recently his colleagues have noticed that he seems to have periods at work when he is easily distracted. Because he is not able to organise a diary, he has missed several crucial appointments.

Speaking to him on the telephone, he seems slow in his speech which is at times slurred. His wife says he has had three episodes of feeling “vacant” in the last month. He alludes to the fact that sometimes he has a headache when he wakes up in the morning. On the telephone, you emphasise that he needs further investigations and make an urgent request for a brain scan and a neurological opinion.

7. Next Steps

COVID-19 has forced a rapid change in the provision clinical services. For MAS, this has in many areas meant a cessation or restriction of access to services for those who are already vulnerable. MAS are all subject to NICE guidelines and the same ethical standards, but local services have different pressures and capacity issues that will shape their individual responses. We are not advocating a single model for MAS. Rather, as we look ahead, we hope that this distillation of ideas and articulation of good practice may be of help to diverse services during the current pandemic, and in reconfiguring services afterwards.

It is likely that COVID-19 will in some shape or form become endemic and so the way services maintain high quality care in the future will require adaptation to a new way of working. This presents a unique opportunity to change the way services are delivered. In some areas of the country, the provision of high-quality remote assessments will improve access to care, where lengthy or difficult journeys to an outpatient clinic would previously have been necessary but impractical. Any financial implications for a change in the way MAS operate would need to be considered, alongside monitoring of risk and the quality of the experience for patients and families.

The group that developed this report is listed in Appendix 1 - we look forward to any comments on the proposals to Alistair.Burns@manchester.ac.uk.

8. Appendices

8.3 Appendix 1

List of contributors (alphabetical order):

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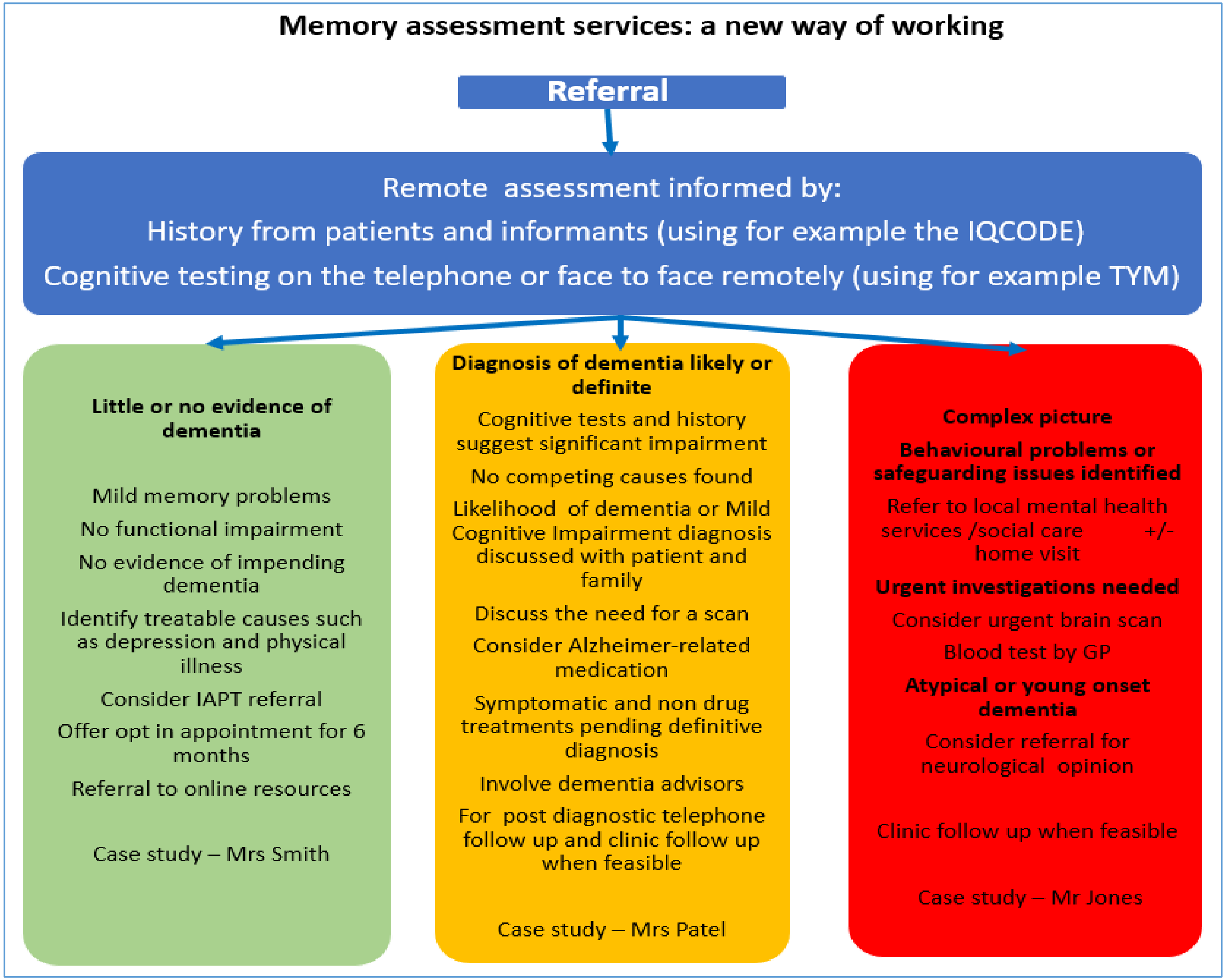
8.4 Appendix 2: Computerized Cognitive Tests

Computerized neuropsychological tests are available, are well validated and have been widely used in clinical trials, where they have been shown to be sensitive to change. The potential advantages include the standardization of delivery, capture of reaction times/processing speed, the absence of learning effects for many of the tests, the value for ongoing monitoring of cognition and the potential to assess multiple cognitive domains in a short testing period. A variety of test are available (Self-ordered search; Paired Associate Learning; Digit Span; Delayed Visual Recognition (Picture Recognition); Verbal reasoning tasks; Digit Vigilance; Choice Reaction Time and Simple Reaction Time) each taking between two and five minutes to administer. They cover memory (working memory and episodic memory), attention, motor speed and executive function that are available on research platforms for studies of brain health in people over 50 such as in the PROTECT study (http://medicine.exeter.ac.uk/protect/)

8.5 Appendix 3



Memory assessment services: a new way of working

Referral

Remote assessment informed by:

History from patients and informants (using for example the IQCODE)

Cognitive testing on the telephone or face to face remotely (using for example TYM)

Little or no evidence of dementia

Mild memory problems

No functional impairment

No evidence of impending dementia

Identify treatable causes such as depression and physical illness

Consider IAPT referral

Offer opt in appointment for 6 months

Referral to online resources

Case study – Mrs Smith

Diagnosis of dementia likely or definite

Cognitive tests and history suggest significant impairment

No competing causes found

Likelihood of dementia or Mild Cognitive Impairment diagnosis discussed with patient and family

Discuss the need for a scan

Consider Alzheimer-related medication

Symptomatic and non drug treatments pending definitive diagnosis

Involve dementia advisors

For post diagnostic telephone follow up and clinic follow up when feasible

Case study – Mrs Patel

Complex picture

Behavioural problems or safeguarding issues identified

Refer to local mental health services /social care +/- home visit

Urgent investigations needed

Consider urgent brain scan

Blood test by GP

Atypical or young onset dementia

Consider referral for neurological opinion

Clinic follow up when feasible

Case study – Mr Jones