

Memory Service Assessments: A New Way of Working



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1. Background

The COVID-19 pandemic inevitably led to changes in the way Memory Assessment Services (MAS) operate. Some MAS staff were redeployed to other activities within mental health trusts, some services closed to new referrals and some clinics put on hold new assessments for people who had already been referred.

The continued ebb and flow of national lockdown restrictions to manage the pandemic has affected waiting times for MAS. People who have memory problems and dementia have also been waiting longer for support.

MAS have had to adapt to provide a safe service during the pandemic, embracing alternative approaches to assessing patients. This includes using telephone and video consultations and providing virtual occupational therapy and neuropsychological testing. This has occurred alongside changing thresholds for investigations like brain scans.

Personalised care remains a central tenet of MAS delivery: evolving to adapt safely to COVID-19 restrictions whilst maintaining patient choice wherever possible, as outlined in the dementia wellbeing in the COVID-19 pandemic pathway published in September 2020 (www.england.nhs.uk/publication/dementia-wellbeing-in-the-covid-19-pandemic/). NHS England and NHS Improvement co-founded the Dementia Change Action Network (DCAN) (www.dcan.org.uk) with the Alzheimer's Society to fully embed the personalised care model in the dementia pathway. Feedback from people living with dementia and their carers was sought via DCAN on the topic of virtual assessment and digital diagnosis and is reflected throughout this report.

The first version of this guidance was published in May 2020. Since then, practice has evolved significantly. This has included revising the terminology. **Virtual assessment and digital diagnosis** has been adopted and is now used to refer to assessment and diagnosis taking place by telephone or video call.

2. General Principles

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

2.1 The service should be needs led

The 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 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 may still come to medical attention through presentation with an acute problem such as delirium, agitation or distressed behaviour. However, as the NHS resumes a 'new 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.

2.2 There should be equality of access

MAS that remained operational during the pandemic relied on virtual assessments. Changing to virtual assessment carries the risk that some patient groups may not have access to a particular technology, which may exclude them. Some patients or carers may lack the necessary facilities for video calls (e.g. computer, webcam, broadband and experience in using them) or have disabilities (e.g. deafness, speech difficulties) that make virtual assessment challenging. They may not be able to afford broadband or lack the home space necessary to have a private conversation.

Similarly, while virtual assessments with people for whom English is not their first language can be conducted via an interpreter, this will take additional time. Together, these problems prevent a seamless and meaningful assessment for a significant minority. While many older people are comfortable using technology, some are not. 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 (www.ethnicity-facts-figures.service.gov.uk/culture-and-community/digital/internet-use/latest#by-ethnicity).

- [...] had no experience in doing video but then she said afterwards that it worked out really well and she just took that leap of faith and now feels much more confident in using it. So, I think there are benefits, it's just investing the time to support people.
- My partner has Alzheimer's, and if she speaks to somebody on the telephone [she says] "No, no, I'm okay. You know, everything's fine". If you put her face to face with somebody, she's much more open - she explains more, she's more truthful about her problems. And if you don't have the truth, and the kernel of the problem and how it's progressing, it's very difficult to get a proper view of how things are.

Feedback from people living with dementia and their carers


2.3 Risk should be assessed and monitored

There are potential risks associated with any rapid change in working practices. The risk is misdiagnosis of a treatable cause of cognitive impairment. Factors to be considered include having a hospital-based brain scan and the potential insensitivity of virtual 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 challenge facing newly configured MAS practices is to manage risk appropriately and be open and transparent with patients and their families about the risks. Clinical training and supervision are key factors in mitigating risk. The GMC has published guidance on remote consultation (www.gmc-uk.org/ethical-guidance/ethical-hub/remote-consultations), as has NHSX (www.nhsx.nhs.uk/information-governance/guidance/using-video-conferencing-and-consultation-tools/#healthcare_worker).



Part of what makes a good remote appointment is that somebody's **chosen** to have that appointment remotely. So, they've been given the information that enables them to make the choice of whether they come and see someone face to face, and the risks that might entail, or whether they choose to have a remote consultation. I think that's really important - it's been their choice.

Feedback from people living with dementia and their carers



3. Appointment Modality

Ensuring a personalised approach and facilitating choice remains of utmost importance. MAS will need to offer a blended model, offering telephone, video and face-to-face appointments. Appendix 3 provides an example of a leaflet and frequently asked questions sent to patients to support informed choice regarding options for memory assessment. It may be beneficial to use multiple formats within one patient pathway. For example, triage by telephone, face-to-face assessment, and diagnosis via video call.

The Royal College of GPs has published top tips for video consultations (www.rcgp.org.uk/about-us/rcgp-blog/top-10-tips-for-successful-gp-video-consultations.aspx) and telephone consultations (www.rcgp.org.uk/about-us/rcgp-blog/top-10-tips-for-covid-19-telephone-consultations.aspx). Further information is available in *Memory Services Considerations: Endemic Covid 19 & beyond* published by the North of England and Yorkshire and Humber Clinical Networks: www.yhscn.nhs.uk/mental-health-clinic/Dementia.php#YHMAS.

In situations where a virtual appointment is not possible (for example, no access to telephone or video; or safeguarding risks identified) and the benefits of diagnosis outweigh the risk, a face-to-face appointment is recommended. Public Health England (PHE) infection prevention and control guidance must be followed for all face-to-face appointments. Up-to-date guidance can be found on the PHE website: www.gov.uk/government/publications/wuhan-novel-coronavirus-infection-prevention-and-control



Feedback from people living with dementia and their carers:

What is a good virtual appointment like?

- One that has been planned. Planning is hugely helpful and enables the person to feel more in control rather than being overwhelmed at the last minute.
- Arrangements and requirements set out in a very clear way beforehand.
- Agreed at a set specific time rather than just 'am or pm'; having to wait in for a morning or afternoon is not helpful.
- In a format that suits the person and carer, at a time that is best for them and lasts an appropriate period (not too long, or too short!).
- One that has been prepared for. Before the appointment it is crucial that the person and/ or carer understands how to access the appointment and is clear about what is going to happen and what to do. You need to check appropriate software etc. is downloaded and that the person understands what the consultation will look like.



A research study designed to understand the patient experience of virtual consultations was published by National Voices, Traverse, Healthwatch England and PPL: www.healthwatch.co.uk/report/2020-08-18/doctor-will-zoom-you-now-getting-most-out-virtual-health-and-care-experience. The publication includes top tips for getting the most out of the virtual health and care experience for patients and health and care professionals.

4. Components of the Diagnostic Pathway

4.1 Referral

Referrals to MAS from primary care dropped sharply in April 2020¹ and while increasing are not yet back to pre-COVID levels. MAS should work with primary care to identify people for whom a memory service assessment would be appropriate, such as post-delirium follow-up, and work with social prescribers and voluntary sector providers to ensure they feel empowered to raise concerns about people who might be exhibiting symptoms of dementia².

Given the continued pressure on primary care, MAS could review the referral sources to ensure that in addition to GP surgery staff, direct referrals are possible from other health and social care professionals including hospital specialists, paramedics and social workers. Pathways could be further developed with hospital specialists diagnosing dementia outside of the MAS pathways where links to the post-diagnostic support networks are well established.

4.2 History

The history of the presenting complaint with collateral information from the family is probably as easy to gather on the telephone for many patients as it is face-to-face. There are exceptions such as deafness, aphasia and the need for an interpreter, and important non-verbal information during the history-giving may be lost such as 'head-turning' to a partner. Issues of consent to contact relatives may arise (considering 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. Time and space should be 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. Advance notice of the questions might be appropriate.

¹ NHS Digital Recorded Dementia Diagnoses <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses>

² London Clinical Network Guidance on remote working for memory services during COVID-19 www.rcpsych.ac.uk/docs/default-source/members/faculties/old-age/nhs-london-clinical-networks---guidance-on-remote-working-for-memory-services-during-covid-19-v2---july-2020.pdf

If the person has someone to attend the appointment with them, it would be good if the doctor had a conversation with them separately to gain a better understanding of the person being assessed.

Feedback from people living with dementia and their carers

The IQ CODE (www.cochrane.org/CD011333/DEMENTIA_using-structured-questionnaire-iqcode-detect-individuals-who-may-go-develop-dementia) is a helpful and valid tool, which allows the patient and family 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.

4.3 Cognitive Assessments

There are about 20 telephone based assessments of cognition available, most of which have been validated (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, 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 (www.ncbi.nlm.nih.gov/pmc/articles/PMC2783323/). Many are subject to copyright restrictions (www.parinc.com/products/pkey/445). NICE has outlined the tests for which there is an evidence base (www.nice.org.uk/guidance/ng97 pages 50-52).

Test Your Memory (TYM, www.tymtest.com) is widely discussed and has been validated against a number of measures. The main TYM tests 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 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 (www.gpcog.com.au/) could easily be carried out on the telephone with the omission of the clock drawing test. The 6 item CIT (www.patient.info/doctor/six-item-cognitive-impairment-test-6cit) can be given on the telephone.

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 (www.mocatest.org/remote-moca-testing/) or MMSE. A remote version of the ACE is available (www.sydney.edu.au/brain-mind/resources-for-clinicians/dementia-test.html). Screen sharing functionality on systems such as Attend Anywhere and AccuRx can support this. 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 virtual 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; they simply measure cognitive function, and all are subject to error through sensory impairment, educational level, and culture or language. Assessment on a cognitive test is more than just administering the test. Much valuable qualitative information can be gathered during the assessment, which adds to the quality and accuracy of the outcome.

The nuances of this will be lost on the telephone and may be less easy to detect on a video assessment. It is important that a clinician uses an instrument with which they are familiar, including the limitations of the instrument. It is also important to recognise the value in flexible approaches, for example, 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.

4.4 Formal Neuropsychological Testing

The British Psychological Society (BPS) Division of Neuropsychology (DoN) has released guidance regarding the virtual administration of neuropsychological assessments (www.bps.org.uk/member-microsites/division-neuropsychology). The risks and benefits of virtual neuropsychological assessment need to be considered. There are significant advantages to conducting neuropsychological assessment by video conferencing rather than telephone, given the greater comparability to face-to-face interaction.

Attention needs to be given to the clinician's familiarity with the virtual administration of the test, and the patient's ability and willingness to engage in virtual assessment. There is an evidence base indicating that valid results can be achieved by virtual administration of neuropsychological tests (e.g. 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 virtual testing.

Where an individual is initially unable to be formally assessed, 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.

4.5 Occupational Therapy Assessment³

The Royal College of Occupational Therapists (RCOT) has published guidance regarding digital occupational therapy (www.rcot.co.uk/practice-resources/occupational-therapy-topics/digital-first-occupational-therapy). While functional assessments are difficult to conduct virtually, it is possible to make observations using video call and this may be useful for assessments of mobility, particularly transfers. Some activities of daily living measures could be administered

³ London Clinical Network Guidance on remote working for memory services during COVID-19 <https://www.rcpsych.ac.uk/docs/default-source/members/faculties/old-age/nhs-london-clinical-networks---guidance-on-remote-working-for-memory-services-during-covid-19-v2---july-2020.pdf>

over the telephone, such as the Bristol Activity of Daily Living Assessment and the Lawton Instrumental Activities of Daily Living. Where possible continue to order and review equipment (home adaptations and assistive technology) via telephone and video link.

Occupational Therapists can assist in establishing routines and supporting carers to find ways of being creative in their caring roles, while still allowing people to have autonomy and independence in their activities of daily living. Carers could send a video indicating difficulties and then recommendations can be made by the Occupational Therapist. Occupational Therapists could offer support and advice to manage behaviours that challenge (the Kingston Standardised Behavioural Assessment can be administered over the telephone) and give ideas regarding meaningful activities for people to engage in while socially isolating.

4.6 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-19 and non-COVID areas of healthcare facilities, this may become easier.

A discussion should be undertaken with the patient and 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 lifetime 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:

- www.yhscn.nhs.uk/media/PDFs/mhdn/Dementia/Dementia%20Diagnosis/Neuroimaging%20guidance/Yorkshire%20and%20Humber%20Neuroimaging%20Guidance%20in%20Dementia%202018.pdf

- www.england.nhs.uk/london/wp-content/uploads/sites/8/2019/09/Neuroimaging-for-dementia-diagnosis-London-Dementia-Clinical-Network.pdf

4.7 Blood tests

These can 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. Previous 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.

4.8 Diagnosis

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 will 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.

[...] it's important for the person who's being assessed for dementia, that they have some moral support and technical support to make them feel comfortable, and also to help absorb the information and soften the impact of a diagnosis that's being delivered.

Feedback from people living with dementia and their carers

4.8.1 Subtyping⁴

If further investigations, e.g. neuroimaging, are required to establish the subtype but are not available then it would be acceptable to give a working diagnosis of unspecified dementia whilst awaiting further investigations. However, neuroimaging is most helpful for 'ruling out' structural pathology and subtyping is generally based on clinical features. Discussing patients with senior colleagues can be a useful alternative where investigations are not available.

One of the diagnostic criteria for Dementia with Lewy bodies is Parkinsonism. Parkinsonian features such as rest tremor, bradykinesia and gait can usually be assessed via a video call. If this is not possible, relatives can be asked questions about walking, including slowness, loss of arm-swing, difficulty turning or navigating small spaces such as doorways, unsteadiness or falls.

4.8.2 Assessment and diagnosis in care homes⁵

A survey by the Alzheimer's Society found that 75% of care homes reported that GPs have been reluctant to visit them⁶, and a survey by the Queens Nursing Institute found that 32% of care home leaders found it difficult to access GP services on behalf of the people they care for⁷. This data suggests that people living in residential adult social care settings may be at greater risk from general health problems being left untreated, as well as COVID-19.

People in care homes are likely to have more advanced dementia; a collateral history from care staff or family members will be helpful in establishing the diagnosis. For diagnosing advance dementia in care homes, the DiADeM tool

⁴ London Clinical Network Guidance on remote working for memory services during COVID-19 <https://www.rcpsych.ac.uk/docs/default-source/members/faculties/old-age/nhs-london-clinical-networks---guidance-on-remote-working-for-memory-services-during-covid-19-v2---july-2020.pdf>

⁵ London Clinical Network Guidance on remote working for memory services during COVID-19 <https://www.rcpsych.ac.uk/docs/default-source/members/faculties/old-age/nhs-london-clinical-networks---guidance-on-remote-working-for-memory-services-during-covid-19-v2---july-2020.pdf>

⁶ Alzheimer's Society. Survey: Caring for a person living with dementia during the COVID-19 pandemic. www.alzheimers.org.uk/COVID-19-report-news

⁷ Queen's Nursing Institute: The Experience of Care Home Staff During Covid-19 www.qni.org.uk/news-and-events/news/major-new-survey-of-care-home-leaders-confirms-severe-impact-of-covid-19/

(www.yhscn.nhs.uk/mental-health-clinic/Dementia/Diagnosis.php#DIADEM) could be used via video conference with the support of care home staff.

Consider the benefits of a diagnosis at this time and if it is in the patient's best interests. For example, will a diagnosis lead to the resident's care plan being updated and support the care home staff to look after them.

Where possible, memory services or Community Mental Health Teams should support care homes by giving advice and guidance on key challenges such as implementing isolation for people who walk with purpose and supporting people with behavioural and psychological symptoms of dementia.

4.8.3 Mild Cognitive Impairment (MCI)

Risk factors for severe COVID-19 infection include advanced age and medical comorbidities such as hypertensive diseases, chronic kidney disease, chronic obstructive pulmonary disease, diabetes and obesity⁸. This population overlaps significantly with at-risk groups for MCI and cognitive decline, representing a baseline neurocognitive frailty that can increase susceptibility to cognitive complications. Thus, the highest risk individuals for severe COVID-19 infection may also represent the most inherently susceptible population for cognitive decline.

MCI occupies a position between normal ageing and dementia: diagnosing it positively, or excluding other causes, gives people who wish it, reassurance and certainty. Following people up is the only way at present to distinguish those people who are getting worse; as such patients with a diagnosis of MCI should be reviewed in Primary Care at least annually. To facilitate this, patients with MCI should be coded on Primary Care Systems using SNOMED CT code 386805003. Appendix D: Submission of Data Items in The Dementia Care Pathway Appendices and Helpful Resources document, refers to how to record/ submit data on MCI:

www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/dementia/nccmh-dementia-care-pathway-appendices-and-helpful-resources.pdf?sfvrsn=af44de5d_10.

⁸ Public Health England: Disparities in the risk and outcomes of COVID-19
www.gov.uk/government/publications/covid-19-review-of-disparities-in-risks-and-outcomes

MCI reviews could be combined with an annual review of other long-term conditions and could take place via telephone or video. It is also an opportunity to talk about dementia risk reduction and to encourage people to take part in research.

Further information about MCI and follow-up can be found in the London Clinical Network non-dementia pathways guidance: www.england.nhs.uk/london/wp-content/uploads/sites/8/2019/07/Final-non-dementia-pathways-V2.pdf.

5. Other aids to diagnosis

- DiADeM is a brief validated tool which is of value in helping to diagnose advanced dementia in care homes.
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.
www.hampshirethamesvalleyclinicalnetworks.nhs.uk/download/dementia-diagnosis-toolkit/
- Online and computerized cognitive testing is also available (see Appendix 2).
www.ncbi.nlm.nih.gov/pmc/articles/PMC6787729/

6. Managing Waiting Lists

The Prime Minister's challenge on dementia 2020⁹ outlined an aspirational national average waiting time for an initial assessment of six weeks following a referral from a GP. A national memory service audit of 85 MAS published by the London Clinical Network in 2019 reported an average waiting time of 13 weeks from assessment to diagnosis, with only 26% of patients receiving a diagnosis within 6 weeks of referral¹⁰.

National lockdown restrictions have resulted in significant waiting lists for MAS appointments. The continued use of virtual assessments and digital diagnosis is likely to aid throughput, provided that clinical management decisions are made and not merely deferred until 'after COVID'. Waiting lists are likely to vary significantly by area and so solutions, such as appointment of locum staff or contracts with private providers, may be of most benefit if implemented at Trust or service level following analysis of local context.

Dementia United, part of the Greater Manchester Health and Social Care Partnership, published recommendations for managing waiting lists as an outcome of the Greater Manchester Memory Assessment Services Summit: www.dementia-united.org.uk/wp-content/uploads/sites/4/2020/10/GM-MAS-Summit-13-August-2020-Output-following-the-event.pdf.

It is important to consider people who drop out of the assessment, at various stages of the pathway. This could be for several reasons including reluctance to attend clinic due to fear of COVID-19 infection; stigma surrounding dementia or anxiety about a diagnosis; however, this represents an extremely vulnerable cohort, who are then 'lost' from the system until there is a crisis, often revealing underlying dementia. A proactive assessment of capacity and consent in this cohort would be beneficial.

⁹ www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020

¹⁰ www.england.nhs.uk/london/london-clinical-networks/our-networks/dementia/key-publications/

The GULP strategy (pictured below) could be used as a starting point to understand and manage waiting lists.

Get to know your waiting list
e.g. how many people have been waiting for more than 12 weeks?

Understand their needs
identify individual needs of patients on the waiting list and signpost pre-diagnostic support wherever possible.

Link with primary care
What do the referrers need? Can they tell you who the urgent referrals are?

Personalised approach
Who can be seen virtually, who needs a home visit? One size doesn't fit all and digital doesn't work for everyone. Contact the patient to ask where they want to be seen.

7. Inclusivity and Accessibility

Equality of access should underpin any change in the way MAS are configured and carry out their activities. Digitally enabled services provide an opportunity to create a more inclusive health and care system, creating more flexible services and opening up access for people who might otherwise find it hard to access in person. The shift needs to be carefully designed to ensure it does not affect health inequalities for others, due to barriers such as access, connectivity, confidence or skills: no matter how people choose to interact with services, they should receive the same levels of access, consistent advice and the same outcomes of care. As set out in the document *Implementing phase 3 of the NHS response to the COVID-19 pandemic*¹¹, care pathways should be tested for achieving a positive impact on health inequalities. Systems should assess empirically how the blend of different methods of engagement (face-to-face, telephone, video) has affected different population groups, including those who may find any particular channel more difficult to access and put in place mitigations to address any issues.

Short-term actions to promote inclusivity and accessibility include wearing rainbow lanyards visible on video calls (ensuring that the wearer understands the lesbian, gay, bisexual and trans significance); providing service leaflets in different languages and ensuring people from Black, Asian and Minority Ethnic (BAME) communities are included in photos and pictures.

Longer-term actions include adapting Cognitive Stimulation Therapy (CST) and other supports for different languages and cultures; extending help to children of people living with dementia; maintaining use of interpreters and identifying community resources specific to key groups.

Services could also consider the use of culturally sensitive tests such as the Rowland Universal Dementia Assessment Scale (RUDAS, www.dementia.org.au/resources/rowland-universal-dementia-assessment-scale-rudas).

¹¹ www.england.nhs.uk/publication/implementing-phase-3-of-the-nhs-response-to-the-covid-19-pandemic/

Evidence indicates that the risk of COVID-19 is significantly higher in BAME communities. The highest age standardised diagnosis rates of COVID-19 per 100,000 population were in people of Black ethnic groups (486 in females and 649 in males) and the lowest were in people of White ethnic groups (220 in females and 224 in males). An analysis of survival among confirmed COVID-19 cases shows that, after accounting for the effect of sex, age, deprivation and region, people of Bangladeshi ethnicity had around twice the risk of death when compared to people of White British ethnicity. People of Chinese, Indian, Pakistani, Other Asian, Black Caribbean and Other Black ethnicity had between 10 and 50% higher risk of death when compared to White British¹². This increased risk should be considered when determining the appropriate appointment format.

The Mental Health Network and Association of Mental Health Providers have co-produced a digital inclusion guide which gives practical tips for mental health providers to make their digital mental health services more inclusive:

www.nhsconfed.org/resources/2020/12/digital-inclusion-guide.

¹² Public Health England: Disparities in the risk and outcomes of COVID-19
www.gov.uk/government/publications/covid-19-review-of-disparities-in-risks-and-outcomes

8. 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 during a 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:

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 alternative resources online, 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.

Medications with anticholinergic effects are known to increase the risk of cognitive impairment and so it is best to reduce their use if possible. Reducing polypharmacy and anticholinergic burden can often be safely initiated after a virtual assessment. The Medichec tool (www.medichec.com) can be used to help clinicians to identify which drugs have an anticholinergic effect on cognition and defines the extent of this effect.

Peri-diagnostic support should actively start at referral. Patients and families can be directed to online resources and sources of information. However, particular care is needed to support and inform those families who lack the facilities or confidence to draw on online resources, including minimising the risks of misinformation. Dementia advisors have a crucial role to play in supporting people and giving advice throughout the diagnostic process and following diagnosis. 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.

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 (iCST) via manual based activities with the family carer can be useful (www.cstdementia.com).

Memory services have developed novel ways to deliver CST using activity packs by post supported by individual CST by telephone, or by virtual CST groups (vCST), as outlined in an Aging and Mental Health paper published in July 2020: www.tandfonline.com/doi/full/10.1080/13607863.2020.1789945. vCST allows people to be brought together from a wider geographical area, which may make provision of language-specific CST groups for culturally diverse groups more viable.

Opportunities for social connection and therapeutic activity remain important, and there are methods to achieve this despite pandemic restrictions. For example, A UK-wide peer support group for women living with dementia was successfully established via Zoom (www.dementivoices.org.uk/group/zoomettes/), with guides on how to use Zoom produced by the group members, and the Alzheimer's Society offers virtual Singing for the Brain groups (www.alzheimers.org.uk/get-support/your-support-services/singing-for-the-brain). There are a number of websites which explore ideas for therapeutic activity and living well with dementia during social distancing, for example:

- Distancing with Dementia (www.distancingwithdementia.org.uk/be-inspired/);

- Health Innovation Network: Activities for older adults during COVID-19 (www.healthinnovationnetwork.com/wp-content/uploads/2020/04/Maintaining-Activities-for-Older-Adults-during-COVID19.pdf);
- Alzheimer’s Society: Activity ideas during coronavirus for people with dementia (www.alzheimers.org.uk/get-support/coronavirus/activity-ideas-dementia).

8.1 Personalised care and support planning

The output of the personalised care and support planning process is a written plan which is clear, simple and precise. It should explain what matters to the person; what care and support the person has; contingency plans; and arrangements for review. Personalised care and support planning should take place as soon as possible after diagnosis (irrespective of where that happens); should be a living, not static document and should cover the aspects outlined in DEMENTIA (pictured below) – see the Good Personalised Care and Support Planning guide for details:

www.england.nhs.uk/publication/dementia-good-care-planning-information-for-primary-care-and-commissioners/



The National Academy for Social Prescribing have developed a Personal Wellbeing Plan Template for use throughout the pandemic, which can be used to summarise what is most important to someone when discussing support someone may need to stay safe at home: www.socialprescribingacademy.org.uk/helpful-new-covid-19-resource-personalised-wellbeing-plan-template/.

8.2 Support for carers

Due to anxieties surrounding COVID-19 and the closure of day centres and respite facilities, support for carers is more important than ever. A survey conducted by the Alzheimer's Society found that 76% of carers reported that their caring responsibilities had increased since the start of the pandemic because of worsening dementia symptoms of the person they care for¹³. 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 (www.toolkit.modem-dementia.org.uk/wp-content/uploads/2016/03/START-Intervention-Summary.pdf).

8.3 Research

There are many research studies that do not involve person-to-person contact. These include online studies and those that can operate via telephone or video call. These studies are continuing as normal so information should still be shared regarding registering interest in research participation following a diagnosis. A number of new research studies have been established on the topic of COVID-19 and dementia: further information on the Join Dementia Research website: www.joindementiaresearch.nihr.ac.uk/.

Strategies such as the development of a 'consent to contact' script for use in telephone or video calls, space in the patient record to document whether a discussion about research has taken place and a line about research in MAS clinic letters may support sign-up for research participation. Discussion about research participation could be pursued by social prescribers, care co-ordinators, memory

¹³ Alzheimer's Society. Survey: Caring for a person living with dementia during the COVID-19 pandemic. www.alzheimers.org.uk/COVID-19-report-news

support workers, and would be appropriate during annual dementia reviews with GPs.

8.4 Patients deemed clinically extremely vulnerable

Individuals considered to be clinically extremely vulnerable (CEV) to coronavirus, based on the criteria set by the UK Chief Medical Officers, have been identified and added to the shielded patient list (SPL). At the start of the pandemic these people were advised to 'shield'. In latter stages of the pandemic, these people are likely to be a priority for vaccination.

A diagnosis of dementia alone does not mean that someone is considered to be CEV, however co-existing health conditions may mean that they are on the SPL. Social isolation, reduction in physical activity, changes to service provision or ongoing arrangements with care providers, and unpredictability and changes in routine caused by adherence to SPL requirements can all increase stress, anxiety and, potentially, worsen symptoms of dementia.

National shielding advice was gradually relaxed and then paused on 1 August 2020 given the reduced risk of exposure to the virus in the community at that time, however many people who have been identified as CEV may still be anxious and concerned about continuing or resuming their daily activities. MAS should be aware of the latest updates and guidance regarding patients who are CEV, which is available on the Public Health England website:

www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19.

NHS England and NHS Improvement formally requested that all providers undertake a series of actions for the provision of NHS care to patients who were shielding. This included the explicit action that “mental health, learning disability and autism teams should ensure that patients under their care who are known to be shielding are proactively contacted and supported through this time”. Doing so allows staff working in these providers to take into account the possible significant effects of shielding on

their patients' mental health and other cognitive or developmental conditions and adjust or bolster care plans accordingly.

To support this proactive contact NHS England and NHS Improvement and NHS Digital have made SPL data available to mental health providers (www.digital.nhs.uk/coronavirus/shielded-patient-list/guidance-for-other-organisations#guidance-for-mental-health-providers).

9. Advance Care Planning (ACP)

Compassion in Dying have published guidance on advance care planning by telephone or video (www.compassionindying.org.uk/library/advance-care-planning-by-phone-or-video/) and a webinar is available via the Dementia Academy on the impact of COVID-19 on advance care planning in dementia (www.dementiaacademy.co/2020/04/24/webinars-admiral-nursing-advance-care-planning-and-remote-clinics-in-a-covid-19-world/).

My future wishes is a resource to support advance care planning conversations with people with dementia in all care settings: www.england.nhs.uk/publication/my-future-wishes-advance-care-planning-acp-for-people-with-dementia-in-all-care-settings/.

West Yorkshire and Harrogate Health and Care Partnership have developed resources to support advance care planning conversations: www.wyhpartnership.co.uk/our-priorities/mental-health/mental-health/dementia.

Emergency care plans can be made in advance to help communication in an emergency and to ensure timely access to the right treatment and specialists. Examples of such plans include the Emergency Health Care Plan (EHCP, www.northerncanceralliance.nhs.uk/deciding-right/deciding-right-regional-forms/) and the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT, www.resus.org.uk/respect).

10. 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 calls require more preparation and raise privacy concerns.

Privacy at the patient end may be difficult. 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 (www.gmc-uk.org/ethical-guidance/ethical-hub/remote-consultations).

Privacy at the healthcare end of the call is also essential. NHS Digital have licenced agreements with AccuRx and AttendAnywhere which should be the preferred platform. If the provider has already established an alternative platform that would fulfil information governance stipulations that would be permissible.

- AccuRx www accurx.com/
- AttendAnywhere
england.nhs.attendanywhere.com/resourcecentre/Content/Home.htm

Where these are not available, during COVID-19 the NHSX Information Governance team advises it is acceptable to use free video conferencing tools such as Skype, WhatsApp and/ or Facetime, if there is no practical alternative, but this should be a temporary measure until a nationally assured product can be procured¹⁴.

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.

¹⁴ NHSX COVID-19 IG advice www.nhsx.nhs.uk/information-governance/guidance/covid-19-ig-advice/

11. Safeguarding

Use of virtual assessment formats has led to new safeguarding concerns and risks which may be harder to detect during a non- face-to-face assessment. This adds a new cohort of health and safeguarding concerns to the likelihood of deteriorating health in those people who are considered to be 'at risk' because of COVID-19 and others for whom there would not have been any health or safeguarding concerns had it not been for COVID-19. Under these circumstances it is particularly important to safeguard those who because of their health or social care needs are at risk of abuse; children and families known to be at risk, those who become at risk and adults with care and support needs.

Bath, Swindon and Wiltshire (BSW) CCG have developed a document about the consideration of safeguarding in all virtual assessments, including both telephone and video calls: www.bswccg.nhs.uk/for-clinicians/safeguarding.

12. Case Studies

To illustrate the new working practices, we offer three illustrative assessments as summarised in the accompanying diagram (see Appendix 4).

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-19 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 video consultation is feasible. She scores 95/100 on the Addenbrookes Cognitive Examination (adapted to be delivered virtually).

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 using 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 virtual 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 not 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.

13. Next Steps

COVID-19 has forced a rapid change in the provision of clinical services. For MAS, this has in many areas meant a cessation or restriction of access to services for those who are already at risk. 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 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 virtual 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 to ENGLAND.DomainTeam@nhs.net.

14. Appendices

Appendix 1: Contributors

List of contributors (alphabetical order):

Clive Ballard; Sube Banerjee; Alistair Burns (Chair); Vicky Cartwright; Julia Cook; Laura Cook; Gemma Clifford; Claire Fry; Sara Humphrey; Jeremy Isaacs; Penny Kirk; Sean Lennon; Chris North; Tolulope Olusoga; Martin Orrell; Bikram Raychaudhuri; Sian Roberts; James Rowe; Colin Sloane; Helen Souris; Mark Thaxter; Amanda Thompsell; Amanda Thornton; Ben Underwood.

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/>).

Appendix 3: Memory Options Leaflet Example

Developed by the Regional OPMH Thinking Group, East of England Regional Clinical Network for OPMH & Dementia.



Next steps

If you are already in contact with a health professional, please discuss your options with them

If you are worried about your memory or someone else's and are not in contact with a health professional already, please contact your GP

Local support is available

If you would like some support to help you decide how you would like to receive your memory assessment, please find information and contact details below, or you can contact the Alzheimer's Society Dementia Connect Support Line on 0333 150 3456

If you don't have access to a computer, i-pad or other device to have an assessment using video, it may be possible to loan you this equipment and provide support for help you use it, if you need it. Details can be found below



We understand that it is a difficult time but you are not on your own

Your memory concerns are important to us – please reach out using any contact numbers on this leaflet



Options for assessing your memory during the coronavirus pandemic



Don't put off seeking advice or help about memory problems

If you are worried about your memory, or that of a family member, assessment and support services are available and accessible now to provide you with reassurance, and to ensure you get the help you need.

Be reassured that, for all appointments Memory Services are operating in line with social distancing guidelines, staff wear PPE and appointments are staggered so that you can feel confident about accessing services safely.

There are different options available for how you have your memory assessment

Some considerations are set out overleaf to help you in making your decision. All the options mentioned overleaf may not be suitable for everyone.

The nurse or doctor you are working with may look at all the information and decide with you which type of assessment is best for you.



Option 1: assessment by telephone

Pros	Cons
<ul style="list-style-type: none"> No risk of infection (coronavirus) No internet needed No need to travel to an appointment 	<ul style="list-style-type: none"> May be difficult if you are hearing impaired May need an extra appointment for physical checks such as blood pressure May need a few telephone calls, rather than one appointment



Option 2: assessment by video using a computer, i-pad or tablet

Pros	Cons
<ul style="list-style-type: none"> No risk of infection (coronavirus) No need to travel to an appointment Extended family members are able to join the appointment using video conferencing Support may be available to help you use the technology Once set up, video assessments are very straightforward 	<ul style="list-style-type: none"> May be difficult if you are hearing or sight impaired Carer, friend or family may be required to support with some memory tests Requires a good internet connection and access to a computer, i-pad or tablet May need an extra appointment for physical checks such as blood pressure May require a few phone calls afterwards



Option 3: assessment face to face in your home

Pros	Cons
<ul style="list-style-type: none"> Health professional able to complete physical checks such as blood pressure on the day No internet needed No need to travel to an appointment May not require additional support from carer, friend or 	<ul style="list-style-type: none"> Risk of infection for patient and carer, friend or family (coronavirus) Health professional needs to wear a face mask which could be a barrier to communication



Option 4: assessment face to face in a clinic

Pros	Cons
<ul style="list-style-type: none"> Health professional able to complete physical checks such as blood pressure on the day No internet needed May not require additional support from carer, friend or family 	<ul style="list-style-type: none"> Risk of infection for patient and carer, friend or family (coronavirus) Health professional, patient and carer, friend or family need to wear a face mask which could be a barrier to communication Need to travel to appointment

Memory Options Leaflet – Frequently Asked Questions

1. Why has this leaflet been produced now?

- The number of recorded dementia diagnoses is significantly lower than pre-COVID pandemic levels.
- In England, between February 2020 and July 2020, it is estimated that there were 7,590 fewer patients referred to memory services than was predicted. If we fail to identify these people there is a risk that they will not access essential healthcare and support, that caring relationships will be strained, and that further pressure will be placed on crisis support services during an already very challenging COVID-19 winter period.

2. Who has produced this leaflet?

- NHSE/I formed a 'Regional Thinking Group' of professionals to achieve deliverables to address key challenges for older people's mental health and dementia during the pandemic
- A Memory Assessment Service (MAS) Sub-group of the Regional Thinking Group formed, including clinicians from memory services, commissioners and voluntary sector representation
- The MAS Sub-group worked with people living with dementia and their carers, through the Alzheimer's Society, to co-produce this leaflet

3. What does the leaflet aim to achieve?

- Inform patients that memory services are open
- Encourage patients with concerns about their memory to come forward
- Inform patients that there are a range of options available regarding how a memory assessment can be conducted during the pandemic to reassure patients that their local services can respond flexibly to their individual needs
- Promote remote/ virtual memory assessment more positively (in response to patient feedback requesting this)

4. Are all four options for memory assessment available?

- The four options in the leaflet may not be available in all local areas, and local offers will change over time in light of circumstances. The purpose is not to give specific information about what is or isn't available locally, but to illustrate that services can respond flexibly during COVID-19 to meet individual needs, and that patients can feel reassured about seeking the help they need.

- There may be some cases in which one or more options is not appropriate for some patients, this will be agreed on a case by case through discussion between the patient/ carer and memory service staff

5. How do I direct patients to local support that may be available?

- There is a blank space on the back page of the leaflet where details of local support service contacts can be written
- You may have locally produced leaflets on support services which can be given alongside this leaflet
- If you are unsure of what is available, the Alzheimer's Society Dementia Connect Helpline number is on the back page of the leaflet. This number can be called by you, or the patient, and this service can provide advice and information on local services

6. Is it safe to be promoting face to face appointments?

- All face to face appointments are being conducted in line with social distancing and infection control guidelines, including screening for COVID-19 upon entry to clinic settings

7. What are the benefits of a patient being assessed for dementia?

Having an assessment for dementia as early as possible has a number of benefits:

- ruling out other medical conditions that may have similar symptoms, such as depression, chest and urinary tract infections, severe constipation, thyroid problems and vitamin deficiencies
- ruling out other possible causes of confusion such as poor sight or hearing, emotional changes and upsets (for example, moving house or bereavement), or the side effects of certain drugs (or drug combinations) the patient may be taking for other conditions
- having an explanation as to why the patient is experiencing their symptoms, so that they can focus on managing them
- getting access to any treatments that may be needed, as well as any relevant information, advice and support (emotional, practical, legal and financial).

Appendix 4: Diagram to illustrate working practices as outlined in case studies

