COVID-19 and dementia: MAS service, activity and learning, in Wessex and Thames Valley

The COVID-19 pandemic has had significant impact on the delivery of NHS services. There is an opportunity to learn from the rapid and necessary service transformation and consider how we recover and return our services.

Executive Summary

The COVID-19 pandemic has had a major impact on dementia services. We sought to ascertain MAS service views across Wessex (Hampshire, Isle of Wight, Dorset) as a peer-support exercise to support recovery planning. The meeting was held for one hour via videoconference on Wed May 6th, 2020 and attended by 33 regional dementia clinicians. To accompany this a survey was also circulated to Hampshire and Thames Valley dementia stakeholders for additional comments. The feedback from the discussion and survey were summarised and form the basis of this report.

Main points

- There has been a substantial reduction in dementia referrals to memory services; it is unclear how rapidly referrals will return to pre-shutdown levels.
- Clinicians vary, but most have focused on risk management, rather than precise clinical diagnosis during recent weeks; this may continue to be an issue if face-to-face consultations remain limited
- The majority of services now use phone and video consultations; this is effective for obtaining clinical history but quite limited for adequate assessment of cognition
- Behavioural risk is relatively easy to quantify via phone, but cognitive assessment tools are blunted, and rely on adequate technology access and capability at both ends
- There is concern that cognitive assessment tools are not sufficiently validated for such an important diagnosis in a remote assessment environment
- Prescription of cognitive enhancing medication (cholinesterase inhibitors, memantine) is hindered by limitations on diagnostic precision, and the inability to obtain the physical assessments needed for safe prescribing
- Ability of primary care to support MAS remains unclear at all stages: referral with provision of relevant history and screening investigations; following diagnosis with medications management and review

- Service restart will be affected by a range of factors including
    - *prior service structure:* especially the balance of home assessments versus clinic assessment
    - *infection control:* requirements and capacity constraints resulting from social distancing and disinfection needs in healthcare environments
    - *availability of investigations:* balance of risk-management versus diagnostic precision including of dementia presence and subtype
    - *requirements for PPE:* different impact depending on where assessment will be performed and the overall service structure
    - *community attitudes:* to the need for dementia assessment, and the risk of contracting COVID-19 from interaction with others (including healthcare staff)
    - *workforce:* levels of absenteeism due to illness or shielding, particularly for BAME staff who appear to be at greater risk of severe infection
    - *screening measures:* the extent (and effectiveness) of screening measures including availability of point-of-care testing
    - *national framework:* which may vary at short notice depending on effectiveness of ongoing social distancing measures and may require rapid change in approach
- Other consequences of prolonged isolation include increase in late-stage presentations of dementia and comorbid conditions; significant impact on carer resilience is likely but not yet understood
- Opportunities include: future use of technology to support dementia assessment and follow-up; increase in virtual support to social care; flexible working arrangements and reduction in NHS environmental footprint

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COVID-19: The big picture

China reported the first COVID-19 related death on 11 Jan 2020. Since then COVID-19 has spread around the world causing significant numbers of deaths, economic uncertainty and societal isolation.

- *11 Jan - first COVID-19 death in China*
- *11 Mar - WHO declares global pandemic*
- *20 Mar - UK in national lockdown.*
- *6 May - over 30,076 UK and 263,381 global deaths due to COVID-19*

In response NHS services rapidly reprioritised services deemed essential for managing the pandemic.

Immediate national challenges included increasing acute care capacity, including the establishment of Nightingale hospitals, Personal Protective Equipment (PPE) provision, sourcing of respiratory support and COVID-19 testing for staff.

More recently, emerging national challenges include the apparent disproportionate risk to BAME groups and COVID-19 impact on care homes.

With reduction in case incidence, focus is now on a second phase with a need to maintain ongoing (but decreasing) COVID-19 care needs and restart non-COVID-19 services. This is also an opportunity to lock in beneficial changes identified including

- backing local initiative and flexibility
- enhanced local system working
- strong clinical leadership
- flexible and remote working where appropriate
- rapid scaling of new technology-enabled service delivery options such as digital consultations.

COVID-19 and Dementia

The cohort of people identified as vulnerable to COVID-19 (aged 65+ and those with comorbidities) significantly overlap with those at risk of cognitive decline and dementia. There is significant risk that this group may be disadvantaged in restart activities unless we identify factors that may affect their service needs.

Factors of particular importance include the following:

- Diagnosis is challenging where face-to-face consultation capacity is limited
- The dementia pathway crosses many organisational boundaries (primary care, secondary care, acute care and social care)
- Underlying infection can alter cognition and behaviour in dementia and increase need for care and support
- Behavioural challenges observed in people with dementia may increase as usual routines and activities change
- Greater difficulty if people with dementia require hospital care, with resulting increase in confusion and distress in changed environment where carer access may be restricted
- An increase in carer burden as families self-isolate and the carer role grows
- Concerns from carers at risk of COVID-19 infection and who will support them if needed

Impact on local dementia services

The Clinical Network is working with Hampshire and Thames Valley commissioning and clinical colleagues to understand the impact on local dementia services.

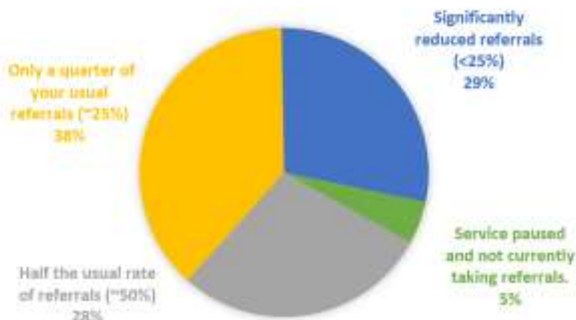
In addition to challenges, recent weeks have highlighted areas of innovation and learning which can be shared and incorporated into our framework for recovery.

There are multiple components to a dementia diagnosis, the prioritising of concerns, the quality of the assessment, cognitive assessment instruments, the location of assessment and the provision of imaging for diagnostic support. All these have been affected by current working arrangements.

Capacity and demand

Access to primary care has been restricted with many GP services prioritising urgent care and using remote appointments. Consequently, most memory assessment services have a reduction in the number of referrals.

Psychiatry services have noted an effect on the quality of referrals, where phone triage of patients in primary care results in less detailed information being provided to MAS in referrals. The loss of qualitative information, often noted incidentally in face-to-face consultations, or through a pattern of repeated presentation, while hard to quantify, is of concern.



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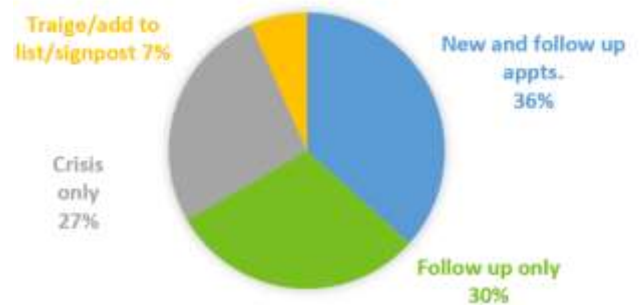
We do not know when the GP referral rate will return to normal, nor how rapid the increase will be.

Memory services themselves have been risk assessed and staff redeployed to other areas of care. Staff sickness and self-isolation has reduced the size of the workforce.



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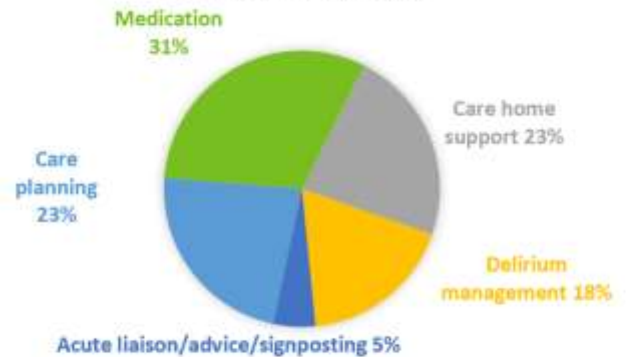

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Where memory services have moved to remote assessment (telephone/video) or home visits (to avoid bringing patients to clinic) this in itself has affected staffing capacity. However, the impact varies across services depending on their prior capacity for

community (home) assessment, and the willingness of patients and carers to be seen in their own homes. This may be influenced by a perception that healthcare workers are at increased risk of infection, and therefore, more easily able to spread it.

Memory Assessment

Memory services are using a variety of methods and tools to prioritise, assess, and diagnose dementia, with some also initiating medication where possible.

Prioritisation and risk

Many memory services have adopted a risk management approach to identify who needs an assessment and how urgently. Typically, this has been driven by the level of behavioural change in addition to the extent of cognitive impairment identified by phone triage. Prioritisation is being supported through:

- through increased use of referral letter information and telephone triage
- Patients showing early symptoms being added to waiting lists until face to face assessment can be conducted.
- Initial telephone assessment with the person of concern and the carer or family member

It is understood that vulnerable and shielded patients will remain in isolation for some considerable time. It is recognised that it is possible to provide many aspects of the service in the current climate and assessment teams feel that it is not appropriate to delay assessment and care when the end point of the present circumstances is still uncertain.

Remote vs Face to Face appointments

Many services have increased the use of telephone and video consultations. With rapid uptake, experience is accumulating as to when remote consultations are sufficient, and where a face to face appointment is still required.

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This knowledge could be used to inform regional guidelines reducing geographical variation in service.

Does the technology work?

Provider technology is useful and being used. There is reported variation in the video quality of Attend Anywhere however this is not consistent.

The greater challenge is the variation in the technology available in private homes. This is compounded by the challenges for this cohort of patients in actually using the technology (age, frailty, comorbidity, technical skills)

Works well where

- The carer present on the call is more familiar with the technology
- Video feed is also available

Works less well where

- People are hard of hearing or have some level of sensory disability
- There is a significant confusion

It is important that clinical impressions are not unduly affected by poor communication or technology skills.

Clinical History and Cognitive testing

Clinicians report that 80% of an assessment can be carried out remotely. Taking a comprehensive history from the patient and co-informant is entirely possible over the phone and does not seem to be a major limitation. There is an impact on the subtle conversational cues that are useful in clinical care.

Cognitive testing is much more challenging, and experience of this varies considerably. Clinical teams are using a range of tools (e.g. MOCA-Blind, MMSE), with varying degrees of success. Some domains are easier to test than others, and all depend on the technological capabilities of patients, carers and healthcare workers involved with the assessment.

Where shared screens are possible there is capacity for showing pictures to help with naming and copying shapes, but this takes practice, and is often not feasible without significant help from a carer.

Many clinicians report a risk-based approach to the current situation, focusing their efforts on identifying behavioural risk and managing accordingly. There is reluctance to use cognitive diagnostic tools where these are not validated for use in this setting. The duration of self-isolation and shielding is likely to influence the willingness of teams to use diagnostic tools to definitively diagnose dementia versus identify risk behaviours requiring immediate intervention.

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Guidelines for remote cognitive testing tools would reduce variation and could inform future evidence base.

If the majority of the assessment is completed remotely this would reduce the contact time required to carry out the remaining components. With appropriate PPE this may be increasingly feasible.

Investigations and imaging

COVID-19 has focussed attention on the purpose and availability of imaging.

Imaging is a valuable part of the diagnostic pathway. The recent Imaging Review conducted by the Clinical Network showed that practice is different in different teams and there are a range of criteria are considered before requesting scans.

Local MAS teams report a switch to use of imaging for risk management, particularly in patients with rapid decline who are not able to be assessed directly. In some areas triage processes trigger a scan request if there is evidence of acute decline in the referral letter.

Structural imaging modalities (CT, MRI) are particularly important for ruling out reversible causes (e.g. subdural, stroke). Definitive diagnosis of dementia, including dementia subtype is more difficult in this setting, particularly with limited formal cognitive testing. The use of functional imaging modalities (SPECT, PET) may become more important as the situation evolves from a risk-management environment, towards one where secure diagnosis (including dementia subtype) is both more necessary, and feasible.

There is considerable uncertainty as to the potential value of blanket imaging in lieu of formal cognitive

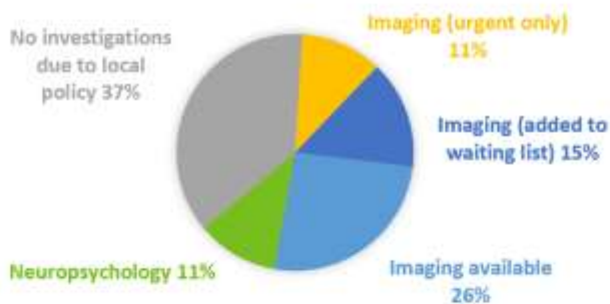
assessment. Irrespective of the merits (or not) of this approach, in practice this is unlikely to be feasible due to imaging capacity constraints and infection control concerns.

Verbal feedback from radiology teams and neuropsychology teams has been successful.

Current availability of imaging

In recent weeks local providers have purposely limited service capacity in order to reduce footfall in hospitals, minimise risk to patients and staff, and focus their service provision on urgent investigations or COVID-related care. Where cognitive decline is associated with a risk marker such as a fall or possible stroke, urgent imaging is available. As the restart gains momentum, social distancing and minimisation of waiting times in imaging facilities will continue to affect capacity.

Decisions on imaging provision are being made locally by individual providers. It remains unclear to what extent imaging prioritisation decisions will be made by individual services, and how referrers may, or may not, be able to influence this. Most providers are adding referrals to waiting lists to be imaged when possible rather than returning referrals A considerable backlog may be developing which will impact on diagnostic capacity for a longer, as yet unquantified, period.



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Once scanning resumes will there may be considerable backlog; this may require an approach to prioritising imaging requests

Some patients are unwilling to travel and attend large hospital sites with higher perceived risk of infection.

'We do not know how long vulnerable and elderly people will be in isolation for and it could be for some considerable time. Would there be a possibility of using mobile scanners based in local smaller locations with improved options for infection control?'

'Could GPs request CT/MRI as part of referral process to inform remote assessment and cognitive testing processes?

Blood tests, pulse rate and ECG

Pre-referral test information is not always available or complete. Some teams have trialled patients taking their own pulse remotely as a proxy for ECG in order to reduce risk with prescription of cholinesterase inhibitor. Success seems variable, and anecdotally, patients and carers find this difficult. The safety of this approach is not clear. The potential for nurse-based home visits to perform these measurements (including ECG) is worth considering.

Some teams are considering including a recent pulse reading to the GP referral template.

Monitoring of blood pressure and pulse rate, can potentially be performed at home using appropriate remote technologies.

Medication management

Use of cognitive enhancers was felt to be problematic, in particular those where there was the potential for cardiovascular side effects (cholinesterase inhibitors). Some clinicians reported the use of memantine as an alternative as the need for prior investigation was minimal, and less impacted in the current climate of remote working where a patient may not have been physically seen by a GP and may not have a recent physical assessment.

In practice, as a symptomatic, rather than disease-modifying treatment, delay in medication initiation until secure diagnosis and adequate physical examination is possible and may be most appropriate. The acceptability of this approach is likely to evolve over time and the duration of shielding recommendations.

Clarification needed on situations appropriate to initiate cognitive enhancing medication in patients who have not been physically seen by any clinician.

Social isolation, shielding and testing

Social distancing and infection control measures are intended to reduce transmission in staff and patient groups and between staff and patients.

PPE and infection control

It is likely that providers will continue to minimise exposure to large high-risk areas (eg hospitals, care homes) wherever possible.

The availability and allocation of PPE in health settings has been challenging. The scale of future PPE use is still being considered with care homes now a priority. The use of public face masks has not been recommended at the time of writing but may yet be recommended as an infection control measure.

The widespread use of face masks as part of PPE could bring other challenges. Those who are hard of hearing or who rely on visual communication clues may struggle. People with dementia who are confused may find PPE additionally threatening/disorientating.

In clinic settings physical precautions can be undertaken, for example: distancing, provision and use of cleaning materials, cleaning between consultations, management of waiting rooms, and temperature taken in waiting area.

Importantly, the location of service provision will be an important factor. If a reduction in footfall in assessment centres is required, community (home) visits may become more important for teams that do not do this routinely. Here the use of PPE and physical distancing will become more important as screening and cleaning will not be in the control of healthcare staff.

Clarification will be needed on type of PPE provision necessary for assessment of individuals in a home environment for both patients and assessment staff.

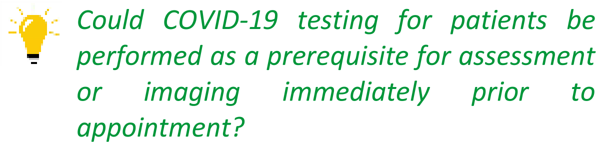
Screening and testing

Low level screening can be done before a clinic or home visit and was implemented prior to the lock-down phase of the crisis. Simple questioning prior to contact of fever and presence of known COVID-19 related symptoms does not take long. This does not take into account asymptomatic carriage, the extent of which remains uncertain.

Other measures that are likely to have an impact on pathways include:

- Provision of ‘hot’ and ‘cold’ areas where people are screened before they enter buildings
- Provision of ‘hot’ and ‘cold’ sites, where assessment can occur on sites felt to be COVID-19 free
- Rapid point-of-care (POC) testing prior to assessment
- Extensive community screening measures and contact tracing

The willingness of patients and their carers to be assessed in their own homes by healthcare staff may become a factor. The potential for introducing infection by healthcare workers is an important concern. A regular system of testing may mitigate this risk and may be less of a risk than bringing people into a formal healthcare environment.

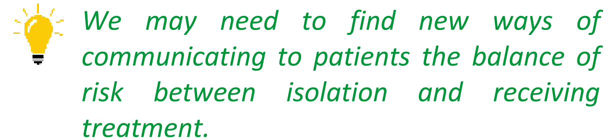


Could COVID-19 testing for patients be performed as a prerequisite for assessment or imaging immediately prior to appointment?

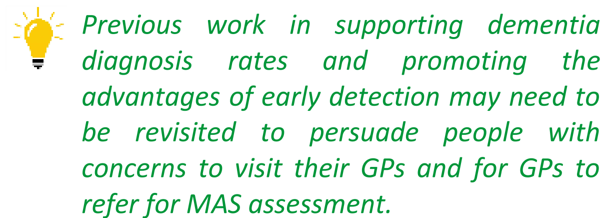
Communication and engagement

The news and social media, together with targeted messaging to vulnerable groups have been important mechanisms for informing communities but have also resulted in a significant level of fear in some sections of the population. Although the full duration of isolation required remains unclear, this may become more relevant over time. Delaying assessment and treatment for a few weeks is very different to delaying for 12 months.

Services may need to find ways of reassuring vulnerable groups and communicating the message that precautions that are being put in place to ensure their safety along the pathway.



We may need to find new ways of communicating to patients the balance of risk between isolation and receiving treatment.



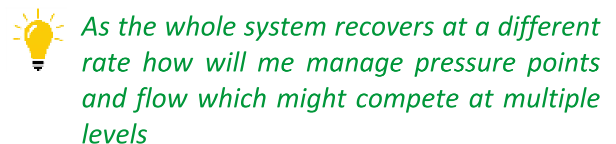
Previous work in supporting dementia diagnosis rates and promoting the advantages of early detection may need to be revisited to persuade people with concerns to visit their GPs and for GPs to refer for MAS assessment.

System wide working

Nationally providers are being encouraged to reopen services over the next 6 weeks with initial emphasis on cancer and cardiovascular services. The expected timescale for reopening the dementia pathway services is not yet defined.

The dementia pathway flows across many organizational boundaries including primary care, memory assessment services, imaging services, community, acute and care home care. Different parts of the system may reopen at different times and each may not have the previous level of business as usual. Some teams are reporting that they are making welfare calls to patients only to find that GP practices and the Alzheimer’s Society have already carried this out in recent timescale giving a disjointed impression to patients.

Some clinicians had raised a concern that vulnerable patients may be coming into less overall contact with health and social care professionals resulting in a potential increase in safeguarding issues.



As the whole system recovers at a different rate how will me manage pressure points and flow which might compete at multiple levels

In the short-term:

- Local: primary care services are keen to maintain remote working in the medium to longer term
- National: care homes continue to be of concern, and infection prevention will presumably be crucial; limits on visiting by healthcare staff will undoubtedly be limited where not absolutely necessary.
- Ordinarily MAS have relied on previous clinicians knowing and personally assessing patients to clarify the history and eliminate comorbid complaints that may be relevant or impacting on the presentation. There is an unquantified risk of being the second or third clinician in a chain who has not physically seen the patient but is relying on phone-based information.

How will much will memory services be able to reply on other parts of the chain to feed through quality information

How could memory services support GPS to do more clinical history taking and safe diagnosis in primary care thus reducing secondary care contacts?

Information sharing

Improved information sharing has been important in managing patients through the COVID-19 pandemic.

Where clinical teams are able to access local clinical systems (CHIE, SystmOne) they have been able to find information to support decision-making e.g. recent ECG results, previous blood results, pulse rates. Historic results have proved to be useful in assessment.

Joined up and up to date information sharing is vital between services.

Post diagnostic support

Dementia care advisory services have also altered working practice as a result of the pandemic. Many are continuing to support people with dementia over the phone or via video links. There is no evidence yet as to the long-term impact of this.

Voluntary post diagnostic support teams may also need a recovery time or have funding challenges impacting on service delivery.

Summary of challenges

- Prioritisation of referrals, particularly where expected information is limited or missing
- Quality of remote assessments including service-user challenges in technology use
- The loss of subtlety in assessment and cognitive testing where face-to-face assessment is not possible
- Secure dementia diagnosis is particularly challenging (dementia presence and dementia subtype), and risk-based assessment predominates
- Initiation and monitoring of cognitive enhancing medication
- Diagnostic imaging availability and purpose
- Potential COVID-19 transmission between staff and shielded groups (PPE)
- Availability and ability to use clinical systems remotely
- System-working for primary, secondary, acute and social care
- Patient engagement, fear and timeliness of actions

Opportunities from COVID-19

COVID-19 has also brought opportunities to do things differently, in particular with respect to virtual communications.

Telephone consultations for follow up patients has proven valuable and if continued as a routine offer may be an efficient method for some going forward.

Clinicians report that virtual MDT and operational meetings have been convenient and easier to attend releasing more time for clinical work. Prescriptions are being emailed to the consultants daily rather than weekly or during the MDT. Prescriptions are consequently available more quickly and MDT meetings can focus on other matters.

Reduced travel where possible will continue to maintain the NHS environmental footprint. Remote supervision is working well in some areas.

For some the opportunity to work from home more flexibly has been beneficial to staff welfare.

Increased telephone support to GPs and frailty teams has resulted in improved confidence to make straightforward diagnoses.

Increased confidence in virtual platforms are leading to developments in other areas e.g. virtual education for carers and cognitive stimulation therapy groups and better information sharing. This may alleviate some of the current group intervention which may not be manageable in the recovery period.

Links to social care and care homes have improved in some areas where an increase in telephone and virtual support to care home staff has been reported.

One team has developed an out of hours COVID-19 crisis support offer which they are considering continuing in the longer term.

A framework for future working

The Dementia Strategy Group comprises experts working along all parts of the Wessex dementia care pathway. They understand the

commissioning and care needs of people with dementia (and carers) and look to identify creative solutions to meet both opportunities and challenges. Their individual roles enable them to affect change in their own areas and to work as a group to support system change.

The information in this report was obtained through a peer-support webinar of Wessex-based dementia clinicians and surveys of MH commissioners, provider and wider system staff across Hampshire and Thames Valley.

Themes emerged on the challenges experienced over the previous 6 weeks and providing current levels of service. Further thoughts also arose on service modifications which may need to continue for this specific cohort of patients.

All memory services reported a reduction in GP referrals but expressed concern that a backlog of referrals alongside current restrictions in assessment and imaging would significantly impact service recovery. Options for additional clinics and weekend working have been raised. Some teams raised concerned that they would continue to have staff shielding and staff from higher risk BAME groups. Supporting/counselling staff who may need a slower return to work and overall staff welfare may be a challenge as the expected backlog is managed.

At the time of writing, guidelines on the process and timing of emerging from lockdown are not available. The nature of any phased or sector approach remains uncertain. The expectations for attaining/maintaining the Dementia Diagnose Rate (DDR) target are also currently unclear.

It seems likely that shielding for vulnerable groups will remain in place for a considerable period. An even larger group of individuals are likely to have concerns about their risk of infection which will lead them to self-limit their interactions with others. There seems likely to be an impact on any activity seen as not essential for care.

There is recent public messaging that the NHS is open for care, however reticence to seek help, reduced physical activity in isolating homes, and less frequent physical heath checks may as yet have impact on early detection of dementia, and other emerging comorbidities.

This group of patients may have had a significant period of social isolation, disruption to everyday life, lack of face to face social interaction and reduced support from neighbours, family and friends. This may in itself be challenging as wider society may recover at a faster rate.

The period of isolation and change in routine is likely to result in increased carer burden and stress which may manifest in later waves. Any delay in return to normal for wider services (respite care, day centres, meals on wheels) will exacerbate this.

Little is known about the longer-term impact on carers of recent events. It is possible that increased carer burden may result in earlier care home admissions. Careers may experience additional sadness that this limited time with their loved ones with dementia has been taken from them by the pandemic.

There is a limited evidence base for remote memory assessment and cognitive testing but with experience, some aspects have become more manageable (remote clinical history). There are risks that the overall quality of dementia assessment may reduce through the impact of pathway fragmentation, and the loss of the more subtle aspects of assessment.

Traditionally care has relied on face to face contact with patients. Technology is available but not infallible and its use is challenging for some. If it is deemed important for at least one clinician in the pathway to assess a patient in person, we should consider how we can best support this clinician to maximize the contact and complete all the face to face requirements in one go. Furthermore, should clarify how we support this clinician to document findings to a standard that is useful to clinicians in the rest of the pathway across complex organisational boundaries. Here, information accuracy and sharing becomes increasingly important.

Decision-making during COVID-19 times has been rapid, flexible and innovative. It has also been complicated, messy and possibly unsafe at times. The ability to think differently has been important, and led to changes in pathways that would have been difficult to otherwise achieve, and may be beneficial in the longer-term.

Preserving what has worked well is an appealing aspiration; maintaining the mindset that things can be done differently may be even more important.