COVID-19 and dementia: The interface between primary care and memory assessment services

The COVID-19 pandemic has had a 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

Primary care and memory services are both working to deliver services in extraordinarily challenging times. An initial webinar looked at the experiences of memory clinics, their capability for receiving referrals and undertaking assessments, the tools and tests available for making a diagnosis and the management of risk.

This subsequent webinar was an opportunity to acknowledge that we need to work as part of a wider system and to understand and explore the interface with primary care. There are new opportunities for the way that we manage care across multiple pathways.

Infection control is crucial to keep patients and staff safe. Patients in Memory Clinics (and their carers) are likely to be at relatively at high risk from Covid-19 typically being older and likely to have comorbidities. Social distancing will remain for some time, and we are likely to have continued reduction in face-to-face contact, so need to make sure that whenever contact occurs it is useful and maximises the opportunity to detect cognitive difficulty, rapidly assess this, and pass information on.

Main points

- Footfall has reduced in primary care due to social distancing activities and anxiety within the community about risk of COVID infection in healthcare settings
- Remote access is being offered and, whilst has limitations, is useful for triage and clinical history taking
- Information in referral letters should be shared in the understanding that it is best that it can be, even if not in the QOF identified timescales (e.g. blood tests)
- There is an opportunity for dementia diagnosis to be made in primary care with appropriate safety-netting
- GP diagnosis will depend on confidence and clarity of presenting concerns: there will be greater confidence in diagnosis of more severe dementia in primary care

- Memory services can offer support and education to Primary care colleagues
- More complex dementia diagnosis will remain challenging in the current environment
- Referring only those cases where there is a specific concern (as part of a risk management approach) would channel flow to memory services for the most complex cases.
- There is limited access to diagnostic investigations with significant backlog and prioritised waiting lists; some patients may decline imaging due to anxiety regarding hospital site attendance
- A working diagnosis and clear follow up plans will mitigate risk in primary and secondary care
- A working diagnosis should not be a barrier to providing post diagnostic support

Interface between primary care and secondary care memory services

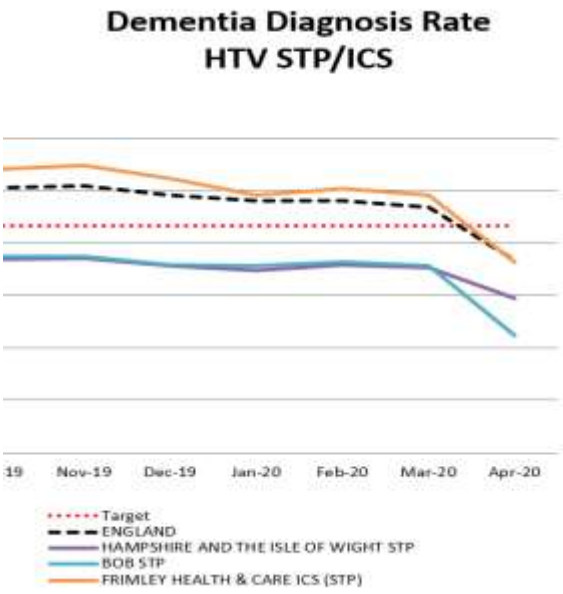
This webinar was held to consider

- current challenges for primary care in delivery of the dementia pathway
- approaches to the primary and secondary care interface
- opportunities for flexibility in local referral pathways to support primary and secondary care
- examples of best practice to share across the region

The webinar was led by Hampshire Thames Valley Clinical Network clinical leads Dr Sian Roberts (Buckinghamshire GP and CCG MH Director) and Dr Chris Kipps (Consultant Neurologist and Senior Clinical Lecturer University Hospital Southampton). Over 70 call participants from across the South East region contributed via the webinar chat channel.

Covid impact on Dementia Diagnosis rate (DDR)

In recent months we have seen significant mortality nationally from coronavirus, and in Hampshire and Thames Valley it appears about 1500 patients with a known diagnosis of dementia have died. A high proportion of these are likely to have been in care homes. The chart shows the significant change in dementia diagnosis rate since March during the COVID pandemic, reflecting the abrupt change in service provision and the difficulty in diagnosing dementia remotely.



In our community, people with dementia are at high risk. It is important that we continue to identify those with memory concerns, find ways to assess and

diagnose dementia, and provide appropriate post-diagnostic support despite the limitations imposed by the COVID pandemic.

What are the current risks?

Primary care and secondary care have moved quickly to increase the use of digital technology and to reduce face to face consultations.

This brings challenges to the continued delivery of routine work while keeping staff and patients safe.

Risks in primary care also include non- or late presentation related to

- a reduction in footfall reducing direct and incidental opportunity for dementia detection
- a fear of coronavirus infection
- patient concern with virtual clinics and preference for delay until f2f becomes available
- difficulty with participating in remote clinics due to changes in cognition

This is a frail group, and although many are more technologically aware than we assumed, patients could be excluded from new ways of working due to the cognitive nature of their complaints.

Current level of face to face consultation in primary care and will this change?

Approximately 90% of primary care patients are currently being seen remotely unless there is a clear clinical need for a face to face appointment.

Patient and staff safety priorities suggest that this will not change in the short-term. With continued remote working, novel ways to enable patients to be assessed, and receive a dementia diagnosis in a safe way are necessary.

What do we lose in remote consultation?

Remote consultation is now common practice in both primary and secondary care. Loss of regular primary care review risks missing the incidental and contextual information that accompanies face-to-face review. We can see a limp as the patient walks in, but not if they are seated at the phone or in front of a computer. The carer shaking their head subtly in disagreement at answers given by the patient are missed if they are off-screen at the time.

Secondary care relies on triage at primary care level, and benefits from the ability in primary care to screen out a range of concerns which memory clinics aren't necessarily used to doing. They cannot rely on this at present, and yet may also be doing consultations remotely, with impaired opportunity to obtain missing or indirectly obtained information.

Clinical risk is inevitable in any clinical pathway, but our normal processes mitigate this. How do we safely manage the situation where risk is no longer mitigated, but simply transferred to a clinical partner who has no mechanism to mitigate it either?

Adapting in primary care?

We need renewed focus on detecting cognitive concerns when assessing people with other long-term conditions. A proactive approach in asking carers and family members in our identification of underlying cognitive issues is needed.

Who do secondary care really need to see?

It is not inevitable that diagnosis of dementia is only for the memory clinic. If cognitive issues are obvious, with appropriate support, a thorough history and backup from family and carers, a diagnosis can be made in primary care.

We should consider where memory clinics add most value, and prioritise those people where there is diagnostic uncertainty or complexity.

Understanding the confidence and capability for primary care dementia diagnosis is important. If there is appetite for this, we should be clear about which tools are needed? Getting this right could help move people more rapidly to the right place to receive appropriate post-diagnostic care.

How are GPs best supported to make a diagnosis?

There is concern in primary care about the risks of (mis)diagnosing dementia, however there are risks to not diagnosing dementia too. Providing support and education may help, and ensuring there are good post-diagnostic services available provides an opportunity to safety net diagnosis.

Initiation and monitoring of medication in patients with dementia is challenging, particularly in patients who have not had a formal diagnosis from a memory clinic. Further support and training might be needed before primary care colleagues feel confident to do this, however prescribing might be an option if supported by direct discussion with secondary care (see end box for training videos on prescribing).

GP screening Tools

Cognitive screening tools such as the 6-CIT or AMT can be used remotely with some consideration as can the GP Cog – although the clock drawing element needs adaptation for this environment (see end box for National Clinical Lead for Dementia paper).

Accepting that there are current limitations in primary care for

- Screening tools
- Blood test
- Physical examinations

referral letters should indicate what has been possible and why further assessment and investigation is being requested from specialised services.

Referral filters

Dementia assessment is currently more challenging for both primary care and secondary care. A careful history, basic cognitive screening test, documentation of what investigations have been performed, and attention to assessment of depression and delirium will help filter referrals to secondary care.

Promoting early pathway steps.

A number of tools are available to initiate diagnostic information gathering early in the pathway to support GPs before involvement of primary care.

A care home staff member may suspect emerging dementia and then use the DiaDem Tool or Wessex Dementia Toolkit to gather relevant information and start the identification and assessment process.

More care homes have now wifi, internet and video conferencing tools available. This is an opportunity to make the most of this new technology and partners in care homes.

Primary Care Networks (PCN) offer opportunities for collaborative working and alternative opportunities to identify memory concerns e.g. community pharmacy.

Blood tests

Patients with suspected dementia usually need investigations such as blood tests to exclude delirium and other organic causes of cognitive decline in timely fashion. Balancing availability of testing and risk of infection with missing the opportunity for correcting reversible causes of decline may need to take into account local COVID prevalence and national guidance. Clinical judgement remains crucial, and no single approach will be appropriate for all.

How risky is a 'wait-and-see' approach?

Time resolves much diagnostic uncertainty in dementia, but is a 'wait-and-see' approach safe, or does reduce the quality of the diagnostic pathway to an unacceptable level? Regular review may mitigate this in part or in full. Things that could be delayed for one month cannot always be delayed for 3 months and things that could be managed differently for 3 months may become critical by 9 months.

Our approach may need to evolve and continue to be innovative, acknowledging, documenting, and monitoring risk.

The role of imaging

Imaging has various purposes: sometimes scans are used to rule a diagnosis out, sometimes to rule it in; we may use imaging to provide reassurance, or to help explain a diagnosis; or to help minimise risk within a fractured clinical pathway.

There are significant capacity constraints for imaging facilities as a result of social distancing, staff reduction, equipment decontamination and patient anxiety increasing DNA rates.

There is a need to characterise the benefits and risks of imaging, during restart and beyond, to address these issues.

Enabling Post diagnostic care

Diagnosis unlocks post diagnostic care and support – this may need review, and acceptance that diagnosis at present is a 'working diagnosis'.

Dementia advisors and care coordinators are more important than ever, and play a crucial role in minimising the effects of social isolation. Within PCNs social prescriber may be able to play an important role.

Although many services many not currently be open e.g. respite and day care, they will eventually reopen and we need to support patients to use them again.

In Summary

We have worked in completely new ways at pace and at scale over the past 3 months. Many uncertainties remain in the period where we restart services, which must limit risk of cross-infection, yet also remain flexible if there are later peaks in COVID prevalence.

The dementia pathway operates across many organisational and service boundaries in health and social care. These individual systems will recover and

return to business as usual at different rates and in different ways.

Whilst challenging our ability to diagnose and manage dementia, this also presents us with many opportunities for working differently.

The impact of dementia on quality of life for an individual and those around them is significant. We cannot simply wait until COVID is over.

Resources and examples of practice

- Alistair Burns report on remote memory clinics
  - http://www.yhscn.nhs.uk/mental-health-clinic/Dementia.php#MAS
- Hampshire Thames Valley discussion on Covid impact on MAS services
  - hosted on the NHS Futures website https://future.nhs.uk/MHLDAcovid19/view?objectId=71692805
- The Wessex dementia diagnostic toolkit can be found here
  - https://wessexsenate.nhs.uk/download/dementia-diagnosis-toolkit/
- The Diadem toolkit is here
  - http://www.yhscn.nhs.uk/media/PDFs/mhdn/Dementia/Dementia%20Diagnosis/2016/DiADeM/DiADeM%20Tool%20Final%2002092016.pdf
- The South West Clinical Network have some useful videos on their website
  - https://www.england.nhs.uk/south/south-west-clinical-network/our-networks/mental-health-network/clinicians-professionals/south-west-clinical-network-our-networks-mental-health-network-clinicians-professionals/
  - HEE dementia training work with care home staff https://www.hee.nhs.uk/our-work/dementia
- Enhanced Dementia Friendly Practices work.
  - http://tvscn.nhs.uk/wp-content/uploads/2019/03/Enhanced-Dementia-Friendly-Practices-Project-2017-Evaluation-Report-Final-151018.pdf
- Kent, Surrey & Sussex Clinical Network in partnership with Coastal West Sussex CCG have developed a dementia medication training package for GPs called TheraDEM. The videos below can be found on YouTube. For further details contact Joanna.gavins@nhs.net.
  - TheraDEM Summary
  - TheraDEM Full version
  - TheraDEM Case Studies
  - TheraDEM DiADeM
  - TheraDEM Driving & Dementia
  - TheraDEM Trailer
- For information on the GP led dementia service model in East Sussex please email Joanna.gavins@nhs.net.

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