GM Memory Assessment Services Summit

Outcomes and Best Practice

Introduction

The GM Memory Assessment Services Summit was held on 13 August 2020 with the goal of discussing the current challenges facing the services during the COVID-19 pandemic and sharing best practice. It was organised by Dementia United[1], part of the GM Health and Social Care Partnership [2].

Discussion at the summit focussed in three areas for which separate seminar sessions were held: Referral, Diagnosis, and Support. This document is the record of the outcomes from those discussions and the best practice suggestions which were shared.

Summary

Despite the challenges which MAS face they are responding with flexibility, innovation, and a willingness to change. Ways have been found to overcome the lack of testing accompanying referrals. Screening and triaging are actively helping to identify those in urgent need of assessment and managing those who now face longer waits.

Alternatives to face-to-face assessment have been trialled and found successful, though problems are acknowledged. A more pragmatic approach to brains scans has been adopted in response to a lower scanning capacity. Ways of offering post-diagnostic support virtually have been delivered successfully to some people living with dementia.

There is a great deal of variety in MAS response to COVID-19 across Great Manchester. Despite the ongoing innovation there is no single best practice. Further work is needed to bring together best practice toward standardisation.

Opportunities for standardisation exist in the form of referrals from GPs, prioritisation of referrals by urgency, categorisation of patients on their need for brain scans, the pathway for prescribing medication, the blend of using virtual and face-to-face consultation, and the level and kind of contact offered to patient while on the waiting list and after diagnosis.

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[1] Dementia United is the Greater Manchester programme for dementia. It aims to make Greater Manchester the best place to live if you have dementia or are caring for someone with dementia

[2] Under an historic devolution deal with the government we have been able to make our own spending decisions since April 2016. The Greater Manchester Health and Social Care Partnership oversees the changes we agreed that we would make, so decisions are made on our doorstep

Summit Agenda

Time	Item
9:30	Welcome and Purpose
9:40	Scene Setting – Professor Alistair Burns, Professor of Old Age Psychiatry, University of Manchester, National Clinical Director for Dementia and Old People's Mental Health • Problems • Good Practice • Questions
9.55	Guidance on Finding Seminar Meetings
10:00	*Break and join your allocated seminar*
10:10	Seminar Sessions running concurrently 1. Referral pathways ○ **Good Practice Speaker:** Professor Alistair Burns – highlighting new ways of working for memory assessment services. ○ **Topics:** Referral pathway, waiting lists, Blended Model, prioritisation of referrals, public information, refusals due to COVID-19. 2. Diagnostic pathway ○ **Good Practice Speaker:** Cerebral Functioning Unit, Manchester Centre for Clinical Neurosciences, Salford Royal NHS Foundation Trust – highlighting good practice in virtual and remote neuropsychological assessment. ○ **Topics:** Alternative to scans, 'Blended Model', history gathering, cognitive tests, neuropsychological assessments. 3. Peri-diagnostic and post-diagnostic support ○ **Good Practice Speaker:** Department of Clinical Psychology, Later Life and Memory Services – Manchester, Greater Manchester Mental Health NHS Foundation Trust – highlighting lessons learned from running a virtual cognitive skills course. ○ **Topics:** Conveying diagnosis, 'Blended Model', follow-ups, medication (titration and review), post-diagnostic support from MAS.
11:40	*Break and re-join the main meeting*
11:40	Summary and Next Steps
12:00	Close

Referral

Due to COVID-19 many services are now working to tackle a backlog of patients awaiting diagnosis, treatment and post diagnosis support. The full extent of this problem may still be unknown due to a lack of patient engagement in services and fewer self-referrals.

This presents services with challenges regarding managing an unprecedentedly large caseload whilst concurrently supporting staff and patients in feeling safe and complying with current social distancing guidelines. In many cases this has necessitated a move towards a blended model for assessments, combining remote and face-to-face assessments, where feasible and necessary. With any approach, services need to be mindful to mitigate risk, ensure equality of access and ensure that support offered is needs-led; with these needs being identified by patients and family members.

The Referral seminar began with an introduction by Professor Alistair Burns, Professor of Old Age Psychiatry at the University of Manchester and National Clinical Director for Dementia, NHS England and Improvement.

Making a Referral

Referrals to MAS mostly come through Primary Care through GPs. Previously the standard referral to a MAS consisted of:

- A description of the problems faced by the patient.
- Blood tests.
- An ECG.

Blood tests and ECGs may be less available now. There is a need to ensure that referrers and the recipients of referrals understand what a minimum referral should include and how the lack of test results can be managed.

- The goal of a referral for somebody with memory problems is to understand whether the problem is significant and identify to correct response. For the patient the goal of a referral may not be the diagnosis but other aspects such as access to services, support, and funding.
- A GP can request blood tests and an ECG concurrently with making a referral to an MAS. They would thus be available to the MAS for assessment though without giving the GP an opportunity to review.
- Blood tests are requested to ensure that there are no physical conditions which contribute to memory problems. This is very rare. It may be that the risks of personal contact when taking blood are greater than the benefit. Where older blood tests are available (up to 6 months old), these can be used instead of retesting.
- ECGs are requested before starting a patient on cholinesterase inhibitors to check for potential concerns. Though they can also be useful for checking for vascular dementia risk factors, they are not needed if no medication is intended. Rowland (2007) suggests that taking a pulse to check for bradycardia can allow for the prescribing of cholinesterase inhibitors. Left bundle branch block and other forms of heart block are of low concern when prescribing cholinesterase inhibitors. Memantine is available without an ECG, where appropriate.
- GPs often do not send a written description of the patient and the problems which have caused the referral. Often the patient’s whole notes are sent, including irrelevant

information, meaning that the receiving MAS must work through the notes to understand the patient. A GP should provide a written description of the patient and the problems they face.

- If a GP is confident that a referred patient has dementia, but is unsure of the type of dementia, they can diagnose as Dementia NOS (not otherwise specified). This will allow the patient to access dementia-related support and services.

- **Recommendations:**
  - GPs should continue to refer patients to the MAS.
  - Cognitive assessment which can be delivered over the telephone are available to GPs.
  - Blood tests and ECGs should be provided where possible, but they are not a reason to delay or stop a referral. Medication can be begun without those tests in many cases.
  - A written description of the patient and the problems they face should be provided to help MAS to understand and screen the patient.
  - Clear information should be provided to GP on what is needed for a referral. This is also made available to PLWD and carers.
  - GPs should provide a diagnosis of Dementia NOS where they are confident to prevent delays accessing support.
  - To look at referrals from care homes using guidance that has already been provided (such as DiADeM) and for people with a learning disability, again using national guidance.

Waiting List Management

Due to the closure of many MAS and reduction in capacity to assess new patients, waiting lists have grown across Greater Manchester. Not all patients can be seen in a timely manner. It is important for MAS to identify patient who need to be seen urgently and to manage those who face longer waiting times.

- Single Point of Entry is important for screening patients for other factors which may have caused a referral. At this stage more information and history can be sought from a patient and their family to understand what problem has caused the referral. Younger patients are be screened for mood problems and referred elsewhere if appropriate. Inappropriate referrals are discussed with the referrer about reasons for rejection and alternatives.
- Accepted referrals are prioritised according to need. The highest priority is those with behavioural problems, younger patients, and those with other risks. The lowest priority are routine assessments.
- The lowest priority referrals which are added to the waiting list should be provided with contact information for the MAS and crisis/support telephone number if available.
- Questionnaires for completion by patients or carers can be sent to those on the waiting list to gather further information. This information can be used to help patients over the phone and manage the waiting list.
- AccuRX can also be used to allow family members to add/send supplementary information to the history provided in the referral.

- Generally, patients on waiting lists are contacted to inform them of waiting times. This letter may not be specific to the MAS but could be trust-wide.
- Those on the waiting list can be provided with information, such as *The Dementia Guide*, to help them clarify their symptoms and help to address some of the worries causing referral.
- Existing patients on medication continue to be contacted by nurses. Others already on the waiting list are contacted to understand their needs.
- A useful mnemonic for managing MAS waiting lists is 'GULP':
    - Get to know your waiting list.
    - Understand their needs.
    - Liaise with Primary Care to know their sense of what's urgent among their referrals.
    - Personalised care.

- **Recommendations:**
    - An agreed system like Single Point of Entry is suggested to screen all referrals when they arrive to prevent delays. Inappropriate referrals should be discussed with the referrer and patients to suggest alternatives.
    - A prioritisation system should be adopted to ensure that level of need is reflected in shorter waiting times.
    - The development of a pathway and flow chart which reflects the prioritisation system.
    - Those on the waiting list should be contacted for more information to aid in assessment and management of the list.
    - Those on the waiting list should be sent information relating to dementia and contact details for crisis and support.

Preparing for an Assessment

- The preference of patients for appointments was mixed. Some services found that, given the choice, most patients chose to be seen in clinic, even with the increased IPC measures. Other found that most were happy with virtual appointments. Those who chose home visits are provided with them, but people would rather have a telephone appointment than a long wait for a face-to-face appointment
- Telephone assessments are difficult due to sensory impairment. Face-to-face assessment provides a better patient experience. Telephone appointments may be more appropriate for follow-ups rather than initial appointments. There's no single approach which fits everybody best.
- The MDT model works wells to maximise consultant time. A nurse can spend time gathering information from a patient and their family. They then present their understanding of the patient at a virtual MDT, involving nurses, therapist, and consultants, which can provide a diagnosis. Diagnosed patients may then spend a shorter time with the doctor.
- Where assessments are undertaken at home admin staff go through a checklist with patients and their family. They check for symptoms of COVID-19, size of rooms, use of PPE, and number of people in the house.

Diagnosis

The introduction of social distancing guidelines has altered the way we approach diagnosis. In many cases this has necessitated a move towards a blended model for assessments, combining remote and face-to-face assessments, where feasible and necessary. Many GM services have already made great strides in adapting to this new way of working.

With any approach, services are needing to be mindful to mitigate risk, ensure equality of access and ensure that support offered is needs-led; with these needs being identified by patients and family members.

The Diagnosis seminar began with a presentation by Dr Matthew Larbey, Clinical Psychologist with the Cerebral Function Unit at Salford Royal Foundation Trust.

Virtual Assessment

Restrictions to face-to-face assessment in clinic have meant that alternative ways to assess have been sought. Both telephone and video assessment have been tried and come with their own challenges.

- It is possible to assess and diagnose through virtual assessment. Though it can be difficult to gather collateral history from family members away from the patient.
- Delivering cognitive assessment virtually may mean that certain kinds of stimulus and response cannot be delivered and captured. Verbal and visual stimulus can be delivered through the audio and camera/screen sharing. Written and drawn response can be collected through posting a workbook to be completed and sent back. Some kinds of physical stimulus and response isn’t possible.
- Most difficult assessments are those which are more dependent on complex response. Executive or motor function are challenging but require being innovative in conclusions and recommendations.
- Patients have typically found virtual assessment acceptable.
- DNA rates are very low but offset by technical failures.
- Virtual assessments can put a high IT burden on patients, but family are often able to help. May be more difficult where people live alone.
- It can be a barrier to rapport building, especially where the assessment is a difficult experience for the patient.
- Audio and video quality can make the problems of sensory impairment worse. Telephone consultations may be challenging for those with speech problems. However, wearing a mask in a face-to-face visit can cause similar communication problems.
- Even with the problems of language disorders a virtual assessment is better than none.
- There is an increased admin burden to running virtual clinics.
- There is a need for video training to allow clinicians to return to it, neuropsychology training, and peer support in starting out with virtual assessments.
- Face-to-face assessments allow for gathering of collateral history from family members in a separate room. It also helps with consent and discussing next steps.
- Collateral information allows for signposting and safeguarding to happen sooner than a face-to-face assessment.

- Hierarchy of assessment modalities, with lower information descending the hierarchy but higher barriers ascending:
    - Face-to-face
    - Video consultation
    - Telephone consultation
- A mixture of more than one way of assessing may be the most useful model, with an enhanced triage over the telephone in addition to a face-to-face assessment. However, the use of face-to-face visits can be an inefficient use of time and cause problems for managing waiting lists.

- **Recommendations:**
    - Face-to-face consultations are still the best way to assess patients but may represent an inefficient use of time given the size of waiting lists.
    - Video consultations should be tried where appropriate and where patients are willing. Assessments may need to be adapted to fit the medium. The support and admin needed for video assessment should not be overlooked.
    - Telephone consultations should be avoided unless necessary due to concerns over sensory impairment, building a rapport, and overall patient experience.
    - Different modes of contact should be mixed to maximise the benefits of each.
    - Care should be taken to collect collateral information from family and carers when they are not present dues to IPC restrictions or cannot be seen away from the patient on a video or telephone call.

Brain Scans

Access to brain scans is more limited than previously and so may not be available as an aid to diagnosis as previously.

- Brain scans are available in GM despite a temporary cessation earlier in the year. While there may be delays for brain scans, there are still many things which MAS can do to progress a patient. The lack of a brain scan should not mean a general delay to all activity with the patient.
- There is no general agreement over whether brain scans are essential or unneeded before diagnosis. Clinical guidance is needed to ensure that there is a minimal standard for the present time. Information on which patient groups would benefit and which do not need a scan.
- Scans do not need to be automatically requested for a patient, but only if there is some uncertainty around type or sub-type of dementia. A patient with significant comorbidity and who has been in decline for a long time may not need a scan.
- Some patients may have had brain scans at other hospitals in the last 6-12 months but accessing them can be very difficult. There needs to be better liaison and access between hospitals and primary care.
- Patients may have been told by their GP when they were sent for referral that they would receive a brain scan. Others may currently be reluctant to visit hospital for a scan.
- Patients could be assessed and given a provisional and general diagnosis without a scan. Discussions can be had with a patient and referrals made in anticipation of a diagnosis.

Scanning can happen at a later point when considering excluding or sub-typing the diagnosis.

- There ought to be a care pathway to support clinicians in the use of scans:
    - Some people do not need a scan (not indicated).
    - Some people would benefit from a scan but not urgent for diagnosis (not necessary now, but good to have a scan when capacity allows).
    - Urgent to diagnose (clinically and diagnostically they need the scan now).
- The need for a scan is determined by the need for other therapies such as assessment from Occupational Therapists or neurological assessment.
- Remote assessment can cause loss of information and may mean heavier reliance on scans.
- CT scans are more helpful than MRI but is heavily dependent on the person reporting and the quality of that report. There needs to be a standard or who reports on the scans with regards to a dementia diagnosis.
- Guidance for requesting scans should include directions to highlight what would be most useful from the scan itself.

- **Recommendations:**
    - Patients can still be sent for brains scans if needed as an aid to diagnosis.
    - Not all patients need brain scans. They should be used where there is uncertainty over the type or sub-type of dementia.
    - Patients should be categorised according to need for scans. Some should be scanned as a priority, others when capacity allows.
    - Patient information is made available at the point of referral in to MAS and CFU on the use of brain scans in order to manage expectations.
    - Requests for scans should be sent with directions highlighting what resulting information would be most useful.
    - Delays to brain scans should not prevent a patient progressing in other areas of support.

Waiting List Management

- Data on waiting lists needs to be broken down to show which referrals haven’t been seen at all and how many are in the diagnostic pathway and being managed to some extent.
- There is a need to develop a flow chart with examples for the recommendations to create commonality of clinical response.

Peri and Post-Diagnostic Support

For people diagnosed with dementia, we know that support in managing symptoms, maintaining physical and social activities, building skills and resilience will help them to live well and may be important to manage disease progression and mitigate unnecessary hospital/clinical visits.

In many cases this has necessitated a move towards a blended model, combining remote and face-to-face appointments, where feasible and necessary whilst keeping to social distance guidelines. With any approach, services need to be mindful to mitigate risk, ensure equality of access and ensure that support offered is needs-led, with these needs being identified by patients and family members.

The Peri and Post-Diagnostic Support seminar began with a presentation by Anna Bax, Assistant Psychologist, and Charlie Jewell, Trainee Clinical Psychologist, with the Later Life and Memory Services in Manchester.

Delivery of Virtual Memory Skills Group

Groups offered by MAS, such as memory skills, can no longer meet in person. Holding virtual support groups is one possible way of providing support to some patients.

- People on the waiting list were contacted and half had the technology and wanted to become involved.
- Group size was halved so that all participants could see each other.
- Laptop is better than phone as it allows participants to see one another.
- Good to have break from slides to allow participants to see one another.
- Two facilitators were needed as higher demands. One facilitator focussed on controlling slides and tech support.
- Screening questionnaire undertaken before sessions to check if they have things such as a quiet space and support for their technology. Guidance sent beforehand to ensure that they know how to join meeting, mute, raise hand, use chat, and so on.
- Admin support important to manage bookings, send out session material, and undertake reminder calls for the session.
- Regular breaks should be given – participants can help manage.
- Important to have an atmosphere of, “we’re all learning” and “let’s have a go”.
- Despite technical difficulties people came back in following weeks.
- Pair work difficult to manage. Whole group activity preferred.
- Direct questions to individuals, with the option not to answer, rather than open questions to the whole group.
- Carers were given the option to join but most preferred only to provide technical help if needed.

- **Recommendations:**
  - Virtual support groups should be offered to patients. Some may be willing to engage and have the technology and skills needed.
  - Smaller groups work better than the usual size for face-to-face.

  - Guidance and questionnaires sent before virtual group meetings helps participants prepare and identify any needs.
  - Admin support is needed to manage and provider reminders to invitees.

Conveying Diagnosis

- Diagnosis may not be given face-to-face currently. Home visits require a risk assessment for staff and a letter for patients and family to let them know what to expect.
- A care plan should identify support needed, agreement about referrals to other services, contingency planning, and so on. It should be sent to the person living with dementia, their carer, and their GP.

Medication

- Assistant practitioners have been undertaking ECGs at home where requested by consultants.
- Memantine has been used instead of anticholinesterase, with a view to switching to the other medication later.
- Concerns over the starting of medication if no consistent monitoring of side-effects by family, GP, or social services. Delays may result in starting medication if no carer support.
- Have kept patients on the same medication. Can increase if carer support available. Titrate much slower than previously.

Post-Diagnostic Support Offer

Post-diagnostic support groups can no longer meet in person. Many have adapted their activities, but others have stopped completely.

- One of the benefits of receiving a diagnosis of dementia is gaining access to the post-diagnostic support. So there needs to be careful consideration of this offer during COVID-19.
- Maintaining phone contacts with a number of clients depending on need. The calls can be used to solve problems. These calls have made people feel less isolated and more supported.
- As a result of groups and day care being stopped some people have gone into crisis, some into respite, and some into hospitals.
- Occupational Therapists are undertaking some face-to-face support, such as walking with people, prioritising those where the carers are most distressed or if people are unable to speak on the phone.
- Patients are offered a choice of coming to the clinic, a home visit, or a telephone call, depending on what they are willing to do.
- Agreement that there is no true substitute for face-to-face contact. However, face-to-face groups may not start until the new year. A blended model based on people's preferences, support, and technology will allow moving forward.
- Larger venues for groups could help to allow social distancing and improve safety.

- **Recommendations:**
    - Recognise that post-diagnostic support is not additional but essential to the well-being of people living with dementia and their carers. A lack of support can cause a significant worsening of their condition.
    - Where technology allows and people are willing some form of support or contact should be offered.
    - Individual telephone calls to those previously receiving support can lessen distress and isolation.

Other Considerations

- Staff capacity is low due to redeployment.
- Changing rules regarding lockdown in Greater Manchester can make it harder to plan.

Next Steps

The information contained in this document represents an overview of the good practice shared at the GM MAS Summit. It includes recommendations based on this good practice. Sharing this document widely will help to ensure the spread of this good practice. This includes not only people working in MAS but also those in Primary Care who make referrals to MAS and linking in with other areas as part of the referral pathway, such as care homes, acute hospitals, learning disability services, and others.

At several points the recommendations call for the use of standards which are left undefined. These are specifically the prioritisation of referrals, guidance for prescribing medicine without blood test and ECG results and need categorisation for brain scans. These require further discussion by relevant clinicians to agree the standards for GM. There is also a wider discussion needed on the blend of virtual and face-to-face consultations given current lower capacity.

These recommendations affect not only the MAS and those working in those services but also those with lived experience: people living with dementia, their carers and families. Any changes made should consider their views and understandings of how the changes will affect them. There is also the question of equity as variation in the practices of MAS may mean differential access to their services across GM. Engagement of people with lived experience is thus necessary as the guidance develops.

A set of standards based on the recommendations in this document is an ambition. A further event may be required to discuss and agree those standards.

All presentations and supporting documents can be found in the zip file attached.

“I just wanted to thank you for the invite to the summit and express that it was certainly a great forum to involved in.”

Attendees

Name	Organisation
Zoe Aldcroft	Dementia United
Richard Atkinson	Greater Manchester Mental Health NHS Foundation Trust (GMMH)
Brigitte Barnes	Pennine Care NHS Foundation Trust
Anna Bax	GMMH
Benjamin Boben	GMMH
Ruth Breslin	Pennine Care NHS Foundation Trust
Alistair Burns	NHSE/I, University of Manchester
Vicky Cartwright	NHSE/I
Jenny Day	Pennine Care NHS Foundation Trust
Amanda Doyle	Pennine Care NHS Foundation Trust
Tony Ellis	GMMH
Katie Elwell	GMMH
Sarah Fox	Dementia Untied / GMMH
Hannah Gaffney	Pennine Care NHS Foundation Trust
Josphat Githaiga	GMMH
Alison Hargreaves	Pennine Care NHS Foundation Trust
Mehran Javeed	GMMH
Charlie Jewell	GMMH
Lyndsey Kavanagh	Dementia United
Jonathan Kaye	Manchester, General Practitioner
Matthew Larbey	Cerebral Function Unit, Salford Royal NHS Foundation Trust
Sean Lennon	GMMH
Helen Martin	Dementia United / Manchester General Practitioner
Carol Ann McCardle	Pennine Care NHS Foundation Trust
Ellen McGowan	Pennine Care NHS Foundation Trust
Clare Mayo	Salford CCG
Jonathan Miles-Stokes	GMMH
Danisa Moyo	GMMH
Jay Palle	Pennine Care NHS Foundation Trust
Chris Pimlott	Tameside and Glossop CCG
Helen Pratt	Dementia United
Maria Roberts	Salford CCG
Salman Siddiqui	Pennine Care NHS Foundation Trust
Amit Sindhi	GMMH
Emma Smith	Dementia United
Jennifer Thompson	Cerebral Function Unit, Salford Royal NHS Foundation Trust
Gill Walters	Dementia United

Nathalie Whittle	GMMH
Josephine Williams	GMMH
Udaju Gammanpila	Pennine Care NHS Foundation Trust