Dementia and Older Adults Mental Health Clinical Reference Group (CRG) Progress Report

February 2015

1.0 Purpose

This paper sets out, for Wandsworth Clinical Commissioning Group (WCCG) Board members, the progress in developing and implementing new initiatives to improve services and outcomes for people with dementia and older adults with mental health needs and their families and carers in Wandsworth. The report outlines the work completed in the past year, the outcomes achieved through the involvement and engagement of patients and their families and carers, as well as commissioning plans for the next year.

The CRG has been meeting every two months, chaired by Dr. Aryan Jogiya, to drive forward the implementation of the strategic intentions included in the WCCG commissioning plans and new service developments to improve outcomes for people with dementia and older adults with mental health and their families and carers in Wandsworth.

2.0 Outcomes

The CRG’s outcomes for 2014-2015 are to:

- Increase the timely diagnosis of dementia in Wandsworth to 67% (set as a national ambition) and provide appropriate quality clinical and non-clinical support post diagnosis to people with dementia and to the carers and families of people with dementia
- To improve the quality of care, reduce distressed reactions and avoidable admissions to hospital in care homes by providing specialist clinical support for staff teams, residents and families
- To enable people with dementia and older adults with mental health needs and their families and carers to live well for longer in the community and access appropriate high quality support at the times when it is needed
- For people with dementia and or functional mental health needs and their carers to receive high quality, compassionate care whether they are at home, in hospital or in a care home.
- To embed and support high quality education and training and culture change right across the health and care workforce

3.0 Dementia Diagnosis Rate

The timely diagnosis of dementia is important in order to: rule out other treatable conditions or causes, access advice, support and treatment (drug and non-drug) and allow people living with dementia and their families to plan and make arrangements for the future. An early diagnosis can help someone with dementia to continue to live independently in his or her own home for longer.

The dementia services that are available to people in Wandsworth were redesigned and launched October 2013 to increase the timely diagnosis of dementia in the Borough. The Memory Assessment service (MAS) is the single point of contact for Wandsworth GPs to refer patients of all ages with memory concerns or suspected dementia for specialist assessment. The MAS team before booking assessment appointments, examines the referrals to check the symptoms, and any that have uncommon presentations, for example, associated neurological signs (e.g. chorea, parkinsonism) and non-memory presentations of dementia (e.g. language disorders) are referred directly by the Memory Assessment Consultant through to the Cognitive Neurology Consultant. The Consultant to Consultant referral has been developed through an excellent working relationship between the two teams and regular clinical case discussions to ensure the person referred sees the most appropriate team for their presenting needs and aftercare. The Alzheimer’s Society provides a Dementia Advisor (DA) that sits within both teams to provide support and signposting after a diagnosis of dementia.

A number of additional voluntary sector services are commissioned including:

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Prime Ministers Challenge on Dementia, (DH, March 2012)
• Dementia Support Workers (DSW) (case study Appendix 2) whom are available throughout the dementia journey to offer a range of non-clinical support for the person with dementia and their families and carers
• Monthly peer support groups and dementia cafes (Cafes WBC commissioned) for people with dementia, their families and carers to access information and share experiences, delivered in partnership with Wandsworth carers’ centre, Age UK, Alzheimer's Society and Furzedown
• A new peer support group for families of people with dementia residing in care homes which is led by the Behaviour and Communication Support Service team within the Wandsworth Older Adults Community Mental Health team

In Wandsworth, the diagnosis rate, the percentage of people estimated to be living with dementia in Wandsworth who have a formal diagnosis, has increased year on year. In Wandsworth, the estimated prevalence of dementia is 2,212 (the number of people estimated to be living with dementia in the Borough), and reaching 67% dementia diagnosis rate translates as 1,482 cases by the end of March 2015. The current dementia diagnosis rate is 56.7% / 1,256 cases formally diagnosed (as of 31st December 2014) and receiving post diagnostic support. Currently the CCG is being advised by the Strategic Clinical Network on a review of the prevalence rate undertaken by NHS England in January 2015, which would increase the local dementia prevalence to 2,230. This proposed increase in the prevalence would reduce the local diagnosis rate to 56.3%.

The Clinical Reference Group has developed an action plan to support achievement of the national target of 67% dementia diagnosis rate by the end of March 2015.

3.1 Directed Enhanced Services (DES)
NHS England have developed two short-term additional enhanced services designed to reward GP practices for undertaking a proactive approach to identify patients with dementia and work with their CCGs to develop services and care packages for patients on their dementia register. The dementia identification scheme is based within care and nursing homes to identify patients in their care who may have symptoms of dementia and offer a dementia assessment. This enhanced service was designed by NHS England to support the Facilitating Timely Diagnosis and Support to identify patients at clinical risk of dementia, offer an assessment to detect for possible signs of dementia in those at risk, offer a referral for diagnosis where dementia is suspected and support the health and wellbeing of carers of patients diagnosed with dementia. Both of the case-finding enhanced services are optional, with the latter, nationally causing debate about whether this approach is an appropriate method to increase the nationally set dementia diagnosis rate due to the risk of unintended consequences.

Locally, the agreed approach to improve both timely diagnosis and access to appropriate post diagnostic support has been to focus on two key priority areas: validating and auditing the coding of newly diagnosed dementia cases and a locally designed approach to case finding within Wandsworth care homes (3.2 and 3.3) alongside our commissioned services (i.e. Memory Assessment Service, Alzheimer's Society)

3.2 Coding
The Memory Assessment Service has been reporting monthly to Commissioners on the latest numbers of diagnosed dementia cases, which has been higher than forecast. Notification of this dementia diagnosis by the Memory Assessment team is sent in a letter to the patient’s GP and should then be recorded on the Practice held dementia registers on EMIS. The Department of Health measures each CCG’s dementia data using the data held on these registers. Currently there is a significant difference in the numbers being reported by the Memory Assessment Service and the recorded number of cases captured on the dementia registers. Data validation is being undertaken in January 2015 by patient lists of all newly diagnosed dementia cases since April 2014 being sent from the Memory Assessment directly to the Patient’s GP Practice to cross reference their systems for accuracy.

The second initiative is the data cleansing of Practice EMIS system to ensure patients are being coding with the appropriate dementia READ code. Wandsworth undertook an incentivised local coding audit exercise between January and March 2014 with a 49% uptake by Practices. As a result of this audit, 40 people were identified with a confirmed diagnosis of dementia that had not been
coded previously. Nationally a data toolkit which aligns with EMIS software has been produced to undertake the same data cleanse of Practice systems, which is being offered, (alongside another opportunity to run the local devised data audit as an alternative) to all Practices who have not participated in this exercise to date.

3.3 Case Finding in Care Homes
NHS England have developed a time-limited additional enhanced service to identify people who have dementia in care homes but have not been recorded on Practice dementia registers or have not been formally diagnosed (section 4.0).

Locally, WCCG had already developed plans to case find within care homes and it has been approved by the National Clinical Lead to continue with these plans. The aim of this work is for Borough care homes (with a registered Wandsworth GP attached to their site) to work collaboratively with link GPs, CCG Commissioners, Medicines Management Team and the Mental Health Trust to identify residents (with the appropriate training, tools and clinical support) with suspected dementia that have not been formally diagnosed and/or coded on GP dementia registers in Wandsworth care homes. A confirmed diagnosis of dementia will enable the provision of quality care, dignity and that ensure that appropriate support is in place for individuals to manage and live well with the condition. This work is being implemented in late January 2015.

4.0 Achievements and Progress
The achievements and progress within Dementia and OAMH CRG since the last annual report have been significantly influenced by patients, families, carers and public involvement and an action plan produced to guide this process (Appendix 1). The CRG have listened to unmet need, attended patient and carer support groups to seek input into their work and captured patient and carer’s voices through all stages of commissioning and service development.

**You said**

- “Someone we can pick up the phone and contact when we need help to provide us with reassurance to avoid a mini crisis”
- “A health person with clout to implement solutions and instruct GPs and other professionals”
- “Extra support when (the) care package changes”

**We did**

- Used the feedback provided by people with dementia, their families and carers to inform the job descriptions of the Dementia Clinical Nurse Specialist team to be based in the community.
- Reviewed the original staffing structure for the team and have opted for a more senior position to lead the team
- This team will provide extra clinical support following a diagnosis of dementia (new and existing) and navigate with other clinical and non-clinical services across Wandsworth
- Produced (in collaboration with carers of people with dementia) a guide to local dementia services. Local guide is now in circulation and to be reviewed in April 2014 by carers and professionals (Appendix 3).
In addition to the progress attributed to the involvement and engagement with patient, families, carers and professionals, a number of service areas have continued to be developed over the course of 2014-15 including:

- Adequate support or training to enable carers to manage and support the person with dementia in their own home. (Carers)
- "It's good when people who have gone through the same thing get to share their experience" (Carers)
- "The care staff are always different, if you get a good one they don't last long." (Carer)
- "I don't always know what my mum means or wants." (Carer)
- "Standardise dementia training." "More training and more training for relatives and paid carers" (Care Homes)
- "I would like to see dementia training as compulsory for all staff to at least foundation level for receptionists and nurses, HCAs and GPs trained to intermediate level" (Primary Care)
- "Staff need to be aware of other causes of distressed reactions i.e. pain, a rapid medical assessment could prevent a potentially catastrophic hospital admission"
- "A co-ordinated approach (to training) with more than one service provider" (Voluntary Sector)

Completed a local mapping of the current dementia training provided across contracted services in Wandsworth and developed a proposed long term delivery plan. The plan, subject to approval, has been informed by the feedback from engagement sessions with carers and professionals and outlines the method of delivering better dementia training to people with dementia, carers and families and professionals. Proposed Priorities in year one of delivery are:

- For more early information and support for people with dementia
- Specialist training provision for unpaid family carers (in groups, online and 1:1)
- Primary Care
- Commissioners to agree on the proposed standard approach to dementia awareness and Train the Trainer programme over the 15 Borough care homes and commissioning intentions of the Behavioural and Communication Support service beyond initial 2 years which offers a training function to both care home staff and relatives as part of their offer
Memory Assessment Service which is the single point of access for adults of all ages with suspected dementia has delivered:

- Higher than forecast number of referrals and subsequent diagnosis and treatment of people newly diagnosed with dementia
- Exceeded the target to achieve 75% of all new diagnosed cases of dementia receiving an individual, accessible and personalised care plan. The plan is a single comprehensive assessment of the patient and carer addressing physical, mental health and social care needs and is undertaken as an additional session, after medical feedback (i.e. at diagnosis of dementia), by a member of the Memory Assessment team. The assessment focuses on what is important to the individual with goal setting and provision of information and support for self-care to achieve these goals. Following the assessment, a personalised care plan is produced to put in place the services required to best support individual health and wellbeing needs in a holistic way. Care plans are continuously reviewed (6 months after diagnosis by MAS and then by GP post discharge from MAS) and updated to reflect the progressive nature of the disease and the changing needs of patients and carers. Qualitative feedback from patients (case study - Appendix 3) and carer’s benefits/outcomes, which also mirror some of the quality outcomes for people with dementia: building on the work of the National Dementia Strategy (DH, Sept 2010) including:
  - Reducing anxiety after initial diagnosis
  - Opportunity to promote and encourage social stimulation/increase social inclusion
  - How, individually, they can plan to live well with dementia
  - Knowing that those around me and looking after me are well supported – coping strategies are discussed at the sessions
  - I understand so I make good decisions and provide for future decision making
  - Self-management – I know what I can do to help myself and who else can help me

- Undertook an audit on ethnicity using the service referrals against Wandsworth demographics to inform changes to increase accessibility to all Borough residents

Behaviour and Communication Support service provides specialist support to staff, residents and families in reducing distressed reactions in our local care homes and in 2014-2015 has:

- Rolled out to 7 Wandsworth care homes with positive feedback across sites
- Identified carers seldom heard from both in the community and relatives of people with dementia in care homes and have developed peer support groups to operate within care homes and the community.
- Received national recognition from DH Deputy General following a visit to a site on National Care homes Day and winning a regional recognition award from South London Membership Council for Service Improvement
- Delivered successful specialist dementia education sessions alongside the Old Age Psychiatrist Consultant, Dr. Andrew Crombie to GPs
5.0 Commissioning Intentions for 2015-16/ Future Plans

The CRG is about to enter a phase of reviewing the success of measures introduced in 2014/15 and is considering the next phase of development of services to support the needs of people with dementia, their families and carers in Wandsworth over the next year. The Commissioning Intentions for the next year are as follows:

I. Implement the Dementia Clinical Nurse Specialist team within the community to enable people to live well for longer and within their own homes and avoid crisis and unnecessary hospital admissions

II. Pending approval, implement the recommended long term dementia training delivery plan across Wandsworth for people with dementia, carers and families, health and social care professionals and contracted voluntary sector services

III. Continue to increase and maintain the timely diagnosis of dementia and access to appropriate post diagnostic support

IV. Complete roll out of the Behaviour and Communication Support service pilot to remaining care homes and carry out a capacity review and mid-term service evaluation

V. Full review of the Memory Assessment Service pilot to inform development of future commissioning plans

VI. Review delivery, performance and effectiveness of the Older Adults Community Mental Health Team function, (specialist support for people with dementia and for older people with functional mental health needs.) The Mental Health Trust is undertaking an operational effectiveness and efficiency work stream to improve productivity. Alongside this work, Commissioners will be redesigning models of care and service delivery based on local needs, gaps and extensive consultation with partners and stakeholders linking with the Mental Health Trust Transformation Programme.

VII. Redesigning the provision of non-clinical support required post diagnosis to improve outcomes of people with dementia and their families and carers

Future plans include:

1. Mapping and redesigning End of Life care pathways for people with dementia

2. Mapping the delirium pathway to understand the needs, issues and gaps in the provision of services to people affected by this symptom

3. Scoping of dementia and older adults mental health commissioned services for accessibility and outcomes to ensure equity for BME communities, age and gender

4. Monitor and review service developments for dementia friendly hospitals and CQUIN\(^2\) for hospitals offering dementia risk assessment to all over 75s admitted to hospital as an emergency

The Dementia and OAMH CRG will continue working in collaboration with other independent services, programmes and CRGs including (but not limited to):

- The Wandsworth Better Care Fund programme to consider how best to take forward integrated commissioning of services, where appropriate, through the Better Care Fund

- Generic non-clinical post diagnostic support for carers, included within the Joint Carers Support Service procurement, to offer a multi-agency approach to delivery, signposting, provide formal links and extend the reach to all potential carers of people with dementia

- The End of Life CRG in the redesigning of care pathways for people with advanced stages of dementia

- Proposals to develop a Care Homes Strategy Group to co-ordinate the work streams operating and new service developments across Borough care homes

6.0 Recommendations

The WCCG Board is asked to:

1. Note the actions to recover the dementia diagnosis rate position before the end of March 2015

2. Note progress in delivering against the commissioning intentions and plans set out in March 2015

3. Note and comment on the plans and priorities for the Dementia and Older Adults Mental Health CRG work plan for 2015-16

\(^2\) Commissioning for Quality and Innovation (CQUIN) - Payment framework enables commissioners to reward excellence, by linking a proportion of healthcare providers’ income to the achievement of local quality improvement goals
## APPENDICES

### Appendix 1 - Dementia and Older Adults Mental Health CRG Patient Public Involvement (PPI Action Plan)

<table>
<thead>
<tr>
<th>Area of work</th>
<th>Actions</th>
<th>Lead</th>
<th>Timeline</th>
<th>Operational process</th>
<th>Progress update</th>
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<tbody>
<tr>
<td><strong>GP and Pathway Leads to actively attend locality patient groups to provide information and seek input into the work of the CRG</strong></td>
<td>GP Lead to attend patient locality groups and update on dementia and OAMH plans for 2014-15</td>
<td>Dr A Jogiya</td>
<td>March 2015</td>
<td>Opportunity promoted to relevant groups and through attendance at Locality Groups</td>
<td>Dr Jogiya has attended 1 patient locality group and be invited to attend another during the year</td>
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<td></td>
<td>Consultations held on all new service developments and/or changes. To date this has included memory assessment service, dementia clinical specialist nurse (service development) and dementia training current position and future needs</td>
<td>Alison Kirby (Commissioner) /Gill Thompson (Project manager)</td>
<td>November 2015</td>
<td>Produce list of stakeholders affected by the proposed service/change and attend meetings, forums and arrange appropriate events to consult</td>
<td>Completed for the services planned for 2014-15</td>
</tr>
<tr>
<td><strong>Listening to the unmet needs being feedback via consultation/s and respond accordingly/factor into CRG work plans where evidence supports the needs being raised</strong></td>
<td>Time factored into each CRG to discuss with voluntary sector representatives and at individual performance meetings with these Providers</td>
<td>Alison Kirby</td>
<td>March 2015</td>
<td>AOB at the next planned CRG in January 2015 and onwards</td>
<td>Effective from January 2015</td>
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<td><strong>Feedback from voluntary sector representatives on the CRG to did they understand what was going on, were they able to contribute and bring the patient/carers' voices to the table.</strong></td>
<td>Consultations held on all new service developments and/or changes. To date</td>
<td>Alison Kirby (Commissioner) /Gill Thompson</td>
<td>Current service consultations</td>
<td>Produce list of stakeholders affected by the proposed service/change and attend</td>
<td>Completed for the services planned for 2014-15</td>
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<td><strong>Patient and carer voice participating at all stages of the development through</strong></td>
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<tr>
<th>Strong links made with dedicated project management support running regular consultations</th>
<th>This has included memory assessment service, dementia clinical specialist nurse (service development) and dementia training current position and future needs</th>
<th>(Project manager)</th>
<th>Ended November 2015</th>
<th>Meetings, forums and arrange appropriate events to consult</th>
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<tr>
<td>Feedback from patients/carers on whether specific work stream documentation is ‘user friendly’ and provides appropriate information</td>
<td>Delivery on this item has been focused on the development of the local guide to dementia services</td>
<td>AK/GT</td>
<td>October 2015</td>
<td>Draft and final versions documents consulted with wide range of audiences at regular meetings, forums, groups etc…</td>
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<td>Carry out dementia environment assessments within various settings and implement changes where highlighted by patient/carer assessors</td>
<td>GP and Pathway lead to recruit representatives to carry out the environment assessment within the individual practices</td>
<td>AJ and IN</td>
<td>August 2014</td>
<td>Assessments undertaken and changes made according to the outcome of the assessment - completed</td>
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<td>Voice of the patient documented throughout to evidence the involvement in the dialogue</td>
<td>To reflect the voice of the patient and outcome of feedback/consultations/concern within CRG minutes</td>
<td>AK and GT</td>
<td>March 2015</td>
<td>Review of CRG minutes scheduled after every meeting</td>
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Appendix 2 - Dementia Support Worker (DSW) Case Study 2014

Mrs Y was referred to the Alzheimer’s Society by the Memory Assessment Service. Mrs Y lives on her own and currently has no paid carers coming in. Her family visit daily. Mrs Y experiences problems due to arthritis in her knees, memory, as well as her hearing and eyesight also getting worse. Mrs Y has a degree of insight into her dementia. Mrs Y does not like to cook for herself and forgets to eat; she has recently lost weight. She does not sleep very well and gets up and down a lot during the night. Upon the home visit, the DSW noted that Mrs Y’s family carers appeared worried about their mother and were trying to ensure that their mother stays in her own home and independent for as long as possible. The DSW explained that the family carer was entitled to a carer’s assessment and provided information about Telecare services that can enable people to live independently for as long as possible. Details of other services were made available to the family to support future planning.

The family carer booked on to the Carers’ Information Support Programme. The DSW suggested some ideas and opportunities to enable Mrs Y to continue to pursue her hobbies. The DSW also explained how some people find making a life story book helpful and informed them about Age UK’s befriending service. The DSW as a result of the discussion with Mrs Y and her family made referrals for:

- Attendance Allowance - Wandsworth Carer’s centre
- Refer to social services for a care assessment and occupational therapy assessment
- Telecare
- Singing for the Brain
- Age UK’s befriending service
- Emailed a link to Brains for Dementia research

The DSW received the following feedback from the family as a result of their initial involvement as follows:

“without ..[the DSW’s] positive and encouraging help I doubt I would have been able to carry on. My brother and I were so impressed by ...[the DSW].

Appendix 3 – Collaborative Care Planning (CCP) delivered by the Memory Assessment Team - Case Study 2014

Mrs. A is a 70 year old lady who lives with her husband. She has multiple co-morbidities including diabetes, high cholesterol and hypertension. Following initial assessment, CT scanning and consultant clinic attendance Mrs A had a confirmed diagnosis of a dementia.

Individual response of coming to terms with her diagnosis was:

“Hearing I had dementia was not an easy thing for me and I wake up in the night and think why me….”

The MAS team member was able to talk through and help Mrs A understand dementia, and the help she could access, as well as reassuring Mrs A that this was a natural response and how to move forward from this was important in her journey. The Collaborative Care Planning session gave her the opportunity to express pertinent feelings and its meaning for her in an unhurried way and assisted her in planning the future. Helping her and the family to understand the relationship between worry and stress and the impact this would have on memory and cognition. Also, the impact of the dementia on her physical health needs and how to keep well.
Family response was that they tried to get on but it was sometimes difficult, so access and details of the Wandsworth carers’ centre were discussed.

The MAS team member was able to discuss the benefits of accessing the local groups and services, something which Mrs A was reluctant to do. It was suggested to her to consider a trial and the benefits of meeting others and re-establishing her interests of the past was discussed with her, one particular interest she had loved in the past was accessible weekly through a local service. She with the help of her husband enrolled to attend and has been finding it an enjoyable experience, on the six months Collaborative Care Planning review recently undertaken she acknowledged how the session had positively contributed to her re-engaging with activities outside the home and accessing these where she is also attending a weekly class at a community centre.

Mrs A was prescribed medication but had not been compliant with these and at the follow up Collaborative Care Planning the MAS team were able to discuss the benefits of taking the medication to support management of the symptoms of dementia. At the six months review, prior to discharge from the MAS service to primary care, the feedback was that the family benefitted from having more knowledge and oversight of these medications as a result of the plans made in the Collaborative Care Planning session by the MAS team, this had also benefited medication compliance.

Appendix 3

Dementia Local Guide