Dementia Diagnosis and Care in England
Learning from Clinical Commissioning Groups
This report details the findings from a series of CCG visits led by Alistair Burns (National Clinical Director for Dementia), with support from NHS Improving Quality. The purpose of the visits was to help build a national picture of what was working well in improving timely diagnosis of dementia and post-diagnostic support, to improve understanding about the challenges faced by CCGs and whether there were any common factors influencing diagnosis rates.
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Executive summary

The provision of high quality care and support for people with dementia and their carers is a top priority for the NHS.

Visits were carried out to a sample of Clinical Commissioning Groups (CCGs) which highlighted the tremendous work being undertaken to improve the timeliness of diagnosis and post-diagnostic support. Several CCGs reported having effective multi-agency groups, with good patient and carer representation to coordinate and drive forward local improvement initiatives. Involvement of the voluntary sector was seen as clearly making a huge difference in many areas.

During the visits a number of challenges were identified, including issues around the role of GPs in diagnosis and follow up, cultural issues, waiting times for assessment and diagnosis, support available to people with early onset dementia and workforce training.

The visits provided an opportunity to listen and learn, and highlight actions that need to be carried out to help and support organisations to fulfil the national ambition by 2015. It is hoped this report is informative and promotes discussion. Further feedback or observations are both welcomed and encouraged.

Key findings

Those CCGs making greater progress in improving dementia diagnosis rates appear to have some common features:

- The local health and care community has a coherent, focused, and clearly led plan of work to improve dementia care
- Commissioners and clinical leaders are active and visible in this pursuit, knowledgeable about what works, and proactively delivering a comprehensive strategy and action plan; working relationships are positive, and it appears that values and ambitions are shared
- Work is proactive, systematic and sustained, rather than reactive and piecemeal
- Dementia care is being mainstreamed within existing health and care services, rather than being framed as something associated with memory services alone
- Ambitions to improve diagnosis are being progressed within the wider context of raising awareness about dementia; improving knowledge and skills of health and care staff; understanding the role of primary care in dementia care, including care of patients living in care homes
- Voluntary and community sector organisations are key partners in the development of strategic plans and as service providers. Investments in this sector are key components of local dementia strategies.
CCGs which have made the greatest improvement in diagnosis rates and post-diagnostic support were able to describe a range of interventions applied across their health and care system. These include:

- High levels of Enhanced Service for Dementia (DES) amongst GPs
- Coding reconciliation exercises and monitoring of QOF performance
- Commissioning dementia advisor services to support timely diagnosis and post-diagnostic support
- Training of health care professionals
- Training for carers
- Advance care planning
- Access to respite care.
1. Introduction

NHS England has an ambition that two thirds of the estimated number of people with dementia should have a diagnosis and access to post-diagnostic support. NHS England are supporting improvement in this area through a wide range of initiatives such as stakeholder engagement, regional events, the development of the prevalence calculator and resource pack, the Enhanced Service for Dementia (DES) and the hospital CQUIN. Other, wider NHS England work around care planning, long term conditions and end of life care is now closely aligned with this work.

While less than half of people with dementia currently receive a diagnosis in England overall, there is two-fold variation between localities. Whereas commissioners, provider and policy leads could suggest reasons for this variation, little intelligence gathering had been undertaken to help identify the factors that may influence this. In order to ascertain if there were any common factors associated with improvement in diagnosis rates, NHS England set out to visit a cross-section of CCGs to find out more. This paper describes the process and sets out the themes arising from the visits.

2. Background

In September 2013 agreement was reached within the Medical Directorate of NHS England that a series of face-to-face visits should take place led by Alistair Burns (National Clinical Director for Dementia in NHS England), with support from NHS Improving Quality (NHS IQ), to meet with a sample of CCG leads for dementia, along with their colleagues. The purpose of the visits was to help build a national picture of what was working well in improving timely diagnosis and post-diagnostic support, to improve understanding about the challenges faced by CCGs and whether there were any common factors influencing diagnosis rates.

Published and publically available information was used to select a cross section of 18 CCGs across England representing those with:

- High and low diagnostic rates (from 2012)
- High and low levels of improvement (between 2011 and 2012)
- High and low ambition rates (for 2013 to 2015)

The vast majority of CCGs approached readily accepted the offer of a visit, one CCG declined, leaving 17 CCGs.

Visits took place between October and December 2013 (three had to be carried out by phone because of difficulties with diaries and, with one, intemperate weather conditions). In advance of each visit, information on the geography, local population, dementia plans, and diagnosis rates was collated together with any further reading that CCG teams thought would

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1 Department of Health (2012), NHS Mandate 2013-14, Department of Health, COI London
2 Department of Health (2013), NHS Mandate 2014-15, Department of Health, COI, London
3 NHS England: Enhanced service specification: Facilitating timely diagnosis and support for people with dementia
4 Department of Health (April 2012), Using the Commissioning for Quality and Innovation (CQUIN) payment framework.
be useful prior to the visit. The purpose of the visit was to hear what was working well, challenges that had been identified, where further help and support was required from NHS England/NHS Improving Quality and whether there were examples of best practice service improvement the CCG would be willing to share more widely. Great care was taken to ensure the emphasis was on mutual learning and support rather than the process being misinterpreted as having a performance management approach. Inevitably, and most informatively, conversations involved many other aspects of dementia care.

The visits were generally well attended and included GPs, commissioners, consultant psychiatrists in old age, consultants in elderly care medicine, lead nurses, local authority leads, voluntary sector, mental health Trust chief executives, and Health and Wellbeing Board representatives. Without exception the teams welcomed the opportunity for an in-depth discussion about a range of dementia related issues concerning dementia care provision.

After each meeting, a thank you letter was sent immediately followed by a longer note of the main discussion points plus any actions agreed.

3. Analysis: diagnosis rates

To assess whether there were common factors associated with diagnosis rates, the CCGs were divided into three groups.

1. High diagnosis/increase group - between the years 2010/11 and 2011/12, six CCGs had a mean diagnosis increases of 7.6% (range 5.0-9.4%). The average diagnosis rate for these six CCGS was 55.5% (2012).

2. Low diagnosis/increase group - between the years 2011/12 and 2012/13, six CCGs had a mean increase 0.6% (range -0.7% to 2.3%). The average diagnosis rate for these six CCGs was 35.8% (2012).

3. High/low ambition group – Three CCGs had some of the highest ambition rates and two CCGs had some of the lowest ambition rates for 2014/15.

3.1 High diagnosis/increase group

Common to most in this group were the following features:

- Sustained joint strategic leadership across health and social care
- Strong clinical leadership for dementia and for frail older people
- A dementia diagnosis pathway and referral protocol which worked well, and was established across local health and care services
- A shared strategic plan, with governance and accountability through local steering groups or partnerships boards
- A community focus on dementia, for example through local Dementia Action Alliances
- Investment in the voluntary and community sector, to provide support and care.

Three of the six CCGs had undertaken an economic evaluation of their diagnosis pathways in order to plan for sufficient capacity at the different stages of the disease.
All six CCGs reported a good take up of the Enhanced Service for Dementia (DES) amongst GP practices.

For the majority of CCGs, assessment and diagnosis of dementia was managed by secondary care provided memory assessment services, supported by referral protocols. One CCG reported GP led diagnosis for selected cases. One CCG had recently retendered their memory service, and despite expecting to reposition it within primary care, it had opted to retain their specialist led memory service to ensure the quality and effectiveness of the service.

Concerns were expressed by some CCGs about developing and maintaining skills in the recognition of signs and symptoms and in managing follow up care among smaller, single-handed practices, where numbers of people presenting would be low.

For the ‘high diagnosis/increase group’, waiting times for assessments showed wide variation. One reported an average 21 week wait for assessment however the majority had maximum waits of 10 weeks. One CCG reported that the review of the local referral pathway, and action to reduce waiting times, had significantly improved the CCG’s diagnosis rate.

Half of this group offered follow-up by secondary care for a limited period, usually around six months. One CCG described difficulties in engaging GPs regarding their plans to move from a specialist led follow up to primary care led follow up for non-complex cases and the consequences for this in terms of training, workload, responsibility and reimbursement. One CCG, where GP follow up had been in place for some time, cited the excellent professional relationships and open access approach between GPs and Old Age Psychiatrists as a key enabler to their shared care approach.

The availability of personalised care plans and advance care planning featured more strongly in the ‘high diagnosis/increase group’, together with the provision of written information. Access to carers’ assessments and respite care were also reported by this group.

The ‘high diagnosis/increase’ CCGs described local health and care systems which integrated and embedded dementia care, for example via local authority reablement schemes, supported housing strategies, and training for domiciliary care staff. They reported a history of good engagement with, and support from the voluntary and community sector, which was providing a significant proportion of the post-diagnosis support.

Five of the six ‘high diagnosis/increase’ CCGs had commissioned dementia advisor schemes from the voluntary and community sector and the sixth was planning to introduce this service during 2014/15.

Two of the six CCGs had undertaken ‘coding clean up audits’, reporting favourable results. Three CCGs cited routine monitoring of diagnosis rates and one shared monthly data with all their practices.

All six CCGs reported comprehensive approaches to post-graduate training and education in dementia care for primary care clinicians and other staff such as GP receptionists. Five of the six CCGs provided training for carers.

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5 Royal College Psychiatrists. English National Memory Clinics Audit: Interactive map (Nov 2013)
6 For four of the six CCGs in ‘low diagnosis/increase’ group, data on waiting times was unavailable from the Royal College of Psychiatrists memory service interactive map.
3.2. **Low diagnosis/increase group**

There are features that are both common to this group, and different from the ‘high diagnosis/increase’ group.

The impression in this group was that the commissioning systems appeared to be subject to distinct challenges. These may be described as:

- Less mature, and/or less than robust relationships between key partners (the CCG, local authorities, Health and Wellbeing Boards; secondary care providers)
- Absence in some of a current and comprehensive multi-agency dementia strategy, addressing both the health and social care needs of the current population living with dementia, and the community’s future population of people living with dementia
- Localities where there had not been significant investment in dementia care or where focus was on other long terms conditions such as cardiovascular disease or diabetes.

Where the practical and technical options for increasing rates of diagnosis were discussed among this group it was noted that:

- The estimate of demand for, and supply of memory assessment services, and associated cost benefits analysis had not yet been undertaken
- Waiting times of current memory services, where known were, or had been long
- Memory service pathway commissioning and/or redesign had either only recently taken place, or was subject to review
- Use of levers such as the Enhanced Service for Dementia scheme (DES) and Dementia CQUIN were reported to be less well adopted and subject to practical difficulties
- Coding audits had not been undertaken though three CCGs had plans to do so
- It was reported that some GPs were reluctant to refer to memory services as there would be little that their patient would be offered, post-diagnosis
- GP and primary health care team training and education in dementia awareness had been limited at present, although it was planned for the future; accessible training, and funding for training were a stated need
- Professional relationships between the acute and primary care clinicians tended to be less well developed. A few reported tensions associated with memory service waiting times and others suggested there may be a culture of nihilism amongst GPs with lower than expected levels of referral
- The absence of dementia advisors (or equivalent) in three of the six was recognised as a likely factor affecting referral rates. One wished to appoint advisors but was currently unable to fund posts. Another had two Admiral Nurses in post but both were contracted for differing roles and it was reported this was leading to some confusion about how to access the service
- The majority reported problems with their memory service using words to describe them as ‘rudimentary’, ‘cobbled’, ‘unclear’, ‘fragmented’. However, two reported major improvements over the past year and both expect to see increases in diagnosis rates in 2014/15
• Assessment and care planning were not discussed however one memory service was known to only provide an information leaflet to people following diagnosis
• Two CCGs had commissioned GP-led memory assessment services, supported by memory nurses and underpinned by a Local Enhanced Service scheme
• The concept of dementia friendly communities was fully appreciated by all CCGs within this group, but in most cases this development was either early in its inception or still at the planning stage.

3.3. High/Low ambition groups

In 2013 all CCGs in England were requested to submit their dementia diagnosis ambition rates for 2013/14 and 2014/15. This was at a time when many dementia leads were not in post, teams were being reformed, and action plans were still in their early stages. Not surprisingly the range of ambition rates submitted varied considerably.

Two of the CCGs visited had plans to achieve over 75% diagnosis rate by 2015, well beyond the NHS Mandate (2013-14). Two of the three CCGs visited had placed their ambition rates below their current performance. Both the above extremes seemed questionable given their 2012-13 diagnosis rates and the work reported to be progressing in their localities. Given this background and the small numbers involved we have been unable to draw any meaningful conclusions or associations either between these two groups.

Findings from these two groups have however been incorporated into the ‘things going well’ and ‘key challenges’ that follow.
4. What’s working well?

The following areas were most commonly reported by CCGs as working well.

- Over half the CCGs reported good working relationships across health, social and other care providers. Many had joint dementia strategies in place and effective steering groups with good voluntary and user representation.

**In Salford** a Dementia Charter has been produced by the Dementia Champions group with ten areas of focus. A city wide Dementia Action Alliance has been established to take forward an action plan that builds on a wide range of acute and community care and support services. Of note is the training programme, Royal College of Nursing carers pilot scheme at Salford Royal NHS Foundation Trust, joint holistic assessment for health and social needs, new models for day services and the ‘Just enough support scheme’ to support those at pre diagnosis stage.

- The same number told us they had good training programmes established for GPs (mainly using protected learning events), community teams, care home staff, council employees. Quite a number had carer education and training programmes in place.

**Sheffield** has an active rolling education programme in dementia across all care providers. Sheffield Teaching Hospitals ensures all new staff receives dementia training relevant to their role. The hospital exceeds the target for the FAIR component of the national CQUIN. There are other learning programmes for professionals and carers of people with dementia who have learning disabilities.
• Many were particularly proud of the success of their local dementia cafes that had enhanced post diagnostic support and very positively endorsed by patients and carers

On the Isle of Wight the Dementia Action Alliance and Age UK have worked with the dementia strategy group to establish four dementia cafes where patients, carers and professionals meet for informal talks and peer support. Weekly sessions in each café are well attended (average 35) by patients, carers and professionals. Since June 2013, 95 people have trained as volunteers, 10 family carers have undertaken educational training and 13 people trained to host a café.

• Others reported the successful redesign of their memory services with measurable impact on waiting times for assessment, diagnostic tests and confirmation of diagnosis. A significant number now offer home based assessment by a nurse or other trained individual, prior to referral to the specialist to discuss diagnosis

Over the past year Havering CCG, along with local partners across health and social care, has redesigned their memory service to address access issues and improve quality. A local awareness campaign, strong sign up to the DES from GPs, nurse led memory assessments, increased clinic capacity, investment in post diagnostic support and a shared care protocol for follow up agreed with GPs, have helped reduce waiting times to three weeks. MSNAP memory service accreditation is pending.

• Improvements to care co-ordination were a key success factor for several CCGs. A large proportion reported having dementia advisors, admiral nurses or equivalents in place, that act as the person’s first point of contact and helped coordinate care. Some were trained to assess and commission care for both health and social care needs

In Wiltshire a dementia adviser service helps people with dementia and their carers navigate the sometimes confusing health and social care system. The service has been jointly funded by the Council and the CCG. Service users have a named adviser who keeps in regular contact and will meet them in their choice of venue, supporting them to live well with dementia from the point of diagnosis by providing personalised guidance and information.

• Several areas reported a marked reduction in the use of antipsychotics both in primary care and within care homes

In 2010 an audit in Portsmouth identified that 17.5% of people registered with a diagnosis of dementia were on antipsychotic medication. This was higher than expected so in partnership with the Older People Mental Health (OPMH) team, a series of prescribing education events were held attended by GPs, specialist clinicians and pharmacists to raise
awareness, review evidence around benefits of antipsychotics, consider case studies and local prescribing practice. A repeat audit in 2011 found that the proportion of people on antipsychotic medication had fallen to 14% and in 2014 this had reduced further to 8%. During the past year the OPMH service has systematically reviewed the prescribing of antipsychotics to all people with a diagnosis of dementia in care homes and nursing homes which is likely to be a major contributor factor in the recent reduction of use. Initiation of antipsychotic drugs for people with dementia are now the exception rather than the norm, only used where clinically appropriate to do and usually following discussion with family and carers.

- Other work ‘going well’ included:
  - Hospital CQUINs
  - Pharmacy input to primary care reviews/care homes
  - GP led diagnosis
  - Care home leaders forum
  - Involvement in research trials
  - Multi-morbidity assessments in primary care
  - Health/care planning.

In **NHS Nene** (Northamptonshire and Corby), work is underway to launch an integrated frail elderly crisis service hub. The aim is for an intensive community-based 14 day treatment and step-down service, with access to social care management. The new hub will pull people in and not just catch them when they are deteriorating, helping to decrease the acute length of stay. This will also support the needs of elderly patients with dementia, estimated to be roughly one third of those accessing the service.
5. Challenges

The following identifies some of the more common issues raised by CCGs.

- Addressing cultural issues with both the public and within professional groups remains one of the biggest challenges for CCGs. Some reported low levels of self-referral due to stigma, others where GPs did not refer due to a perceived lack of benefit. Several are attempting to address this through awareness campaigns, training and investment in post support services.
- The role of GPs in diagnosis was a topic of debate in many areas. Some had agreed local protocols with acute providers, but most worked on the principle that everyone identified with a memory problem required referral to the memory service. Diagnosis of dementia for residential and nursing home residents was a particular issue and the appropriateness of brain scans to confirm diagnosis.
- Several CCGs reported a lack of engagement and some resistance amongst GPs regarding the transfer of non-complex follow up to primary care, especially in areas with limited care coordination support. Additional pressure and responsibilities for already stretched primary care services was the main cause for resistance rather than the ability to manage such cases.
- CCGs raised concerns about how people with mild cognitive impairment are managed in primary care, and within a dementia referral pathway. The GP role in diagnosis was an issue raised by several teams.
- Concerns about how best to manage patients with Korsakoff’s syndrome, resulting from alcohol misuse, was raised by two CCGs.
- One CCG had identified that GPs were reluctant to code people as being at risk of dementia amid beliefs that this would have an adverse effect on private insurance.
• A number of CCGs were concerned about the care of people with early onset dementia and the lack of local support provision suitable for their age and interests particularly regarding access to psychological support
• Concerns were also raised about the standards of care in primary care, and for patients living in care homes. Lack of staff training in the care for people with dementia, advance care planning and end of life care were key issues in some areas
• Several CCGs were keen but did not have the capacity to undertake some economic modelling within dementia care, to fully understand the benefits of one service model over another that would help them develop commissioning plans
• Less common issues raised by CCGs included local authority/Health and Well-Being Board engagement, use of CT and MRI scans, care in care homes, single handed GPs, ‘any qualified provider’ issues, test recording in the QOF cycle, access to counselling support, ECGs and if primary care or memory service responsibility
• The data did not favour a diagnosis pathway model. It is noted that the ‘most improved’ group of CCGs commissioned diagnosis pathways by specialist memory services. Half of this group had undertaken an evaluation of their respective pathways and were using data to inform investment
• Follow up by memory services post-diagnosis, GP-led follow up, and the use of shared care protocols varied across all groups studied
• The role of general practice/primary care in dementia care particularly around diagnosis was highlighted as an area for further development by a number of CCGs.

6. Conclusions

It is recognised that this study is subject to limitations owing to the limited sample size and the qualitative nature of the discussions. However, the intention of the study was to elicit learning about why some health [and care] systems are making significantly greater progress in improving dementia diagnosis rates than others.

There are a number of features which delineate this group, the most evident being that:

• The local health and care community has a coherent, focused, and clearly led plan of work to improve dementia care. This work is systematic and sustained; it has a history and continues to build over time
• Commissioning and clinical leaders are active and visible in this pursuit, knowledgeable about what works, and proactively delivering a comprehensive strategy and action plan; working relationships are positive, and it appears that values and ambitions are shared
• This work is proactive, systematic and sustained, rather than reactive and piecemeal
• Dementia care is being mainstreamed within existing health and care services, rather than being framed as something associated with memory services alone
• Ambitions to improve diagnosis are being progressed within the wider context of raising awareness about dementia, improving knowledge and skills of health and care staff, understanding the role of primary care in dementia care, including care of patients living in care homes
• The voluntary and community sector is a key partner in terms of strategic planning and as a provider; development of the voluntary and community sector as a provider, and investment in this sector are key components of local dementia strategies.

The CCGs which had made greatest improvement were able to describe a range of interventions applied across their health and care system. These included:

• High levels of Enhanced Service scheme (DES) take up amongst GPs
• Commissioning dementia advisor services to support timely diagnosis and ongoing support
• Commissioning carer training
• Advance care planning
• Access to respite care.

7. Suggestions and next steps

It is suggested that CCGs in collaboration with NHS England Area Teams and Strategic Clinical Networks:

• Continue to identify ways to improve diagnosis pathway and diagnosis rates and incorporate within the CCG assurance processes
• Develop comprehensive locality based dementia action plans to improve diagnosis pathways, covering access; assessment; and post-diagnosis support
• Examine local diagnosis pathways and services against NICE Dementia Quality Standards, to inform local strategic planning and partnership working.

Next steps:

• To develop an economic model for diagnosis to help inform commissioners
• Explore further, and with NICE, the role of GPs in diagnosis and use of brain scans
• Provide further guidance to CCGs and GPs on ‘what a good dementia pathway’ looks like for both diagnosis and post diagnosis support
• Identify ways to better articulate the benefits of diagnosis
• Continue to develop and share good practice
• Develop and disseminate a brief self-assessment check list, adopted from this study, for CCGs to utilise.

Further insight into examples of what’s working in other areas is welcomed, the challenges CCGs are experiencing in improving diagnosis and post diagnostic support, and any further thoughts on what NHS England can do to support this work. Comments and suggestions should be sent to Alistair Burns, National Clinical Director for Dementia (alistair.burns@nhs.net).
8. Acknowledgements

Thank you to all those CCGs who responded so positively to the visits, offered their valuable time and who were so open and honest about their services.

Clinical Commissioning Groups visited

1. East Riding of Yorkshire
2. Harrow
3. Havering
4. Herefordshire
5. Hull
6. Isle of Wight
7. Leicester City
8. Nene
9. Portsmouth
10. Salford
11. Scarborough and Ryedale
12. Sheffield
13. South East Hampshire
14. Swindon
15. West Cheshire
16. West Norfolk
17. Wiltshire