

National Dementia Policy in England – Responding to the Prime Ministers Challenge

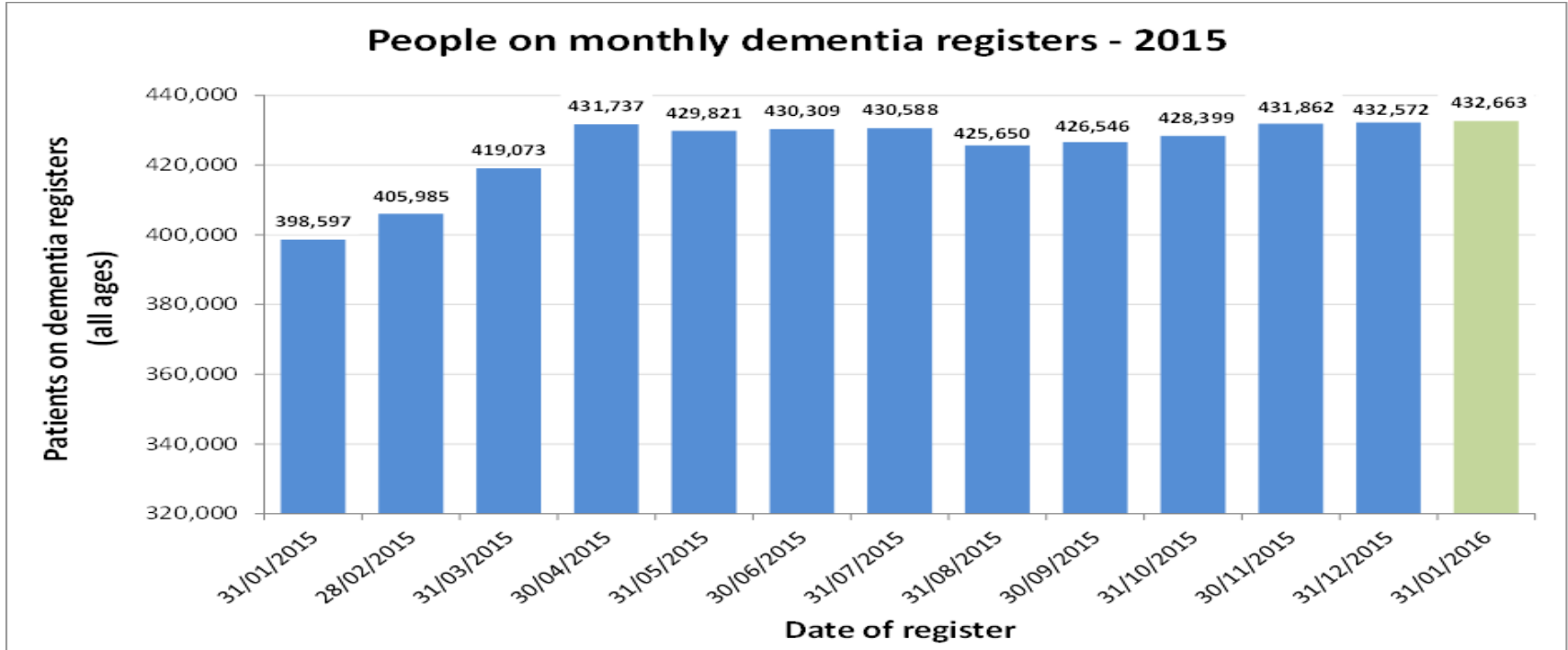
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National Performance: Dementia

The ambition in the NHS mandate of two-thirds of people living with dementia receiving a formal diagnosis has been achieved and surpassed as at end of November 2015



To maintain the national rate, ensuring that people living with dementia have access to a diagnosis sufficiently early to plan and access their support needs, it will be important to:

- Address variation in diagnosis rates, in particular CCGs that are significantly adrift of the ambition (at least 10%). These are the group of organisations at highest risk and merit national level attention.
- Maintain and continually improve rates of diagnosis, including in the group of CCGs who have met and exceeded the ambition.

NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 <p>Risk of people developing dementia is minimised</p>	 <p>Timely diagnosis, integrated care plan, and review within first year</p>	 <p>Access to safe high quality health & social care for people with dementia and carers</p>	 <p>People with dementia can live normally in safe and accepting communities</p>	 <p>People living with dementia die with dignity in the place of their choosing</p>
<p>“I was given information about reducing my personal risk of getting dementia”</p>	<p>“I was diagnosed in a timely way”</p> <p>“I am able to make decisions and know what to do to help myself and who else can help”</p>	<p>“I am treated with dignity & respect”</p> <p>“I get treatment and support, which are best for my dementia and my life”</p>	<p>“I know that those around me and looking after me are supported”</p> <p>“I feel included as part of society”</p>	<p>“I am confident my end of life wishes will be respected”</p> <p>“I can expect a good death”</p>
<p>STANDARDS:</p> <p>Prevention⁽¹⁾ Risk Reduction⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Diagnosis⁽¹⁾⁽⁵⁾ Memory Assessment⁽¹⁾⁽²⁾ Concerns Discussed⁽³⁾ Investigation⁽⁴⁾ Provide Information⁽⁴⁾ Care Plan⁽²⁾</p>	<p>STANDARDS:</p> <p>Choice⁽²⁾⁽³⁾⁽⁴⁾ BPSD⁽⁶⁾⁽²⁾ Liaison⁽²⁾ Advocates⁽³⁾ Housing⁽³⁾ Hospital Treatments⁽⁴⁾ Technology⁽⁵⁾ Health & Social Services⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Integrated Services⁽¹⁾⁽³⁾⁽⁵⁾ Supporting Carers⁽²⁾⁽⁴⁾⁽⁵⁾ Carers Respite⁽²⁾ Co-ordinated Care⁽¹⁾⁽⁵⁾ Promote independence⁽¹⁾⁽⁴⁾ Relationships⁽³⁾ Leisure⁽³⁾ Safe Communities⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Palliative care and pain⁽¹⁾⁽²⁾ End of Life⁽⁴⁾ Preferred Place of Death⁽⁵⁾</p>

References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.

COMMISSIONING GUIDANCE:

- Develop commissioning guidance based on NICE guidelines, standards and evidence-based best-practice.
- Agree minimum standard service specifications, set business plans, mandate and resources.
- Work with ADASS, PHE & other ALBs on co-commissioning strategies to provide an integrated service.

MEASUREMENT:

- Develop Quality, Access and Prevention metrics to form the basis of the CCG scorecard.
- Identify data sources and agree with HSCIC, et al on the extraction processes.
- Set 'profiled' ambitions for each metric, to form the basis of the transformation plan.

TRANSFORMATION, RESEARCH, INNOVATION, TECHNOLOGY, PATIENT ENGAGEMENT AND BEST-PRACTICE:

- Transformation: using CCG scorecard to set & achieve a national standard for Dementia services.
- Intervention: Intensive Support Team to provide 'deep-dive' support and assistance for CCGs that fall short.
- Innovation: Intel from Research, Patient involvement, best-practice and technology to influence change.

Preventing Well

“I was given information about reducing my personal risk of dementia”

Rationale - There is good evidence that a proportion (estimates vary but 10-15% has been cited) of diagnoses of dementia could be avoided by rigorous management of eg vascular risk factors – what’s good for your heart is good for your head. Prevention is led by PHE and information about risk reduction is included in current Health Checks. Prevention messages have the advantage of portraying a positive approach and are relevant to a generation younger than those generally thought to be affected by dementia .

Draft Expectation - By 2020, every person will be aware of their personal risk of dementia which can be part of the NHS Health Check, identifying people at higher risk of developing dementia and relatives of people with dementia.

Diagnosing Well

“I was diagnosed in a timely way and told about research”

Rationale - Initiatives have been implemented by NHS England and taken up by CCGs with a demonstrable improvement in diagnosis rate over the last year. Monthly contact with CCG's and mobilisation of regional teams has been successful as well as getting support for the clinical message of the benefits of a diagnosis. New treatments for the commonest cause of dementia, Alzheimer's disease, have a realistic prospect of success which will change the landscape of assessment and treatment with key roles for NICE, NHS Improvement and NHS England in the provision of clinical advice and commissioning guidance .

Draft Expectation - By 2020, the overall diagnosis rate maintained at two thirds of the estimated number of people with dementia, every person who wishes a diagnosis will have that, where clinically appropriate, within six weeks of referral (or the timescale advised by the National Collaborating Centre for Mental Health). Variation in performance will reduce by 10% pa such that all CCGs will be compliant by 2021 and 25% of people with dementia will have been given the opportunity to take part in research.

Supporting Well

“Those around me and looking after me are supported”

Rationale - Post or peri-diagnostic support is key. People with dementia and their carers say that support ideally needs to be from a single person, the advice needs to be bespoke and the response needs to be timely. Dementia advisors are a key part of this and a three step approach of support (ABC) with Advice and information provided in general, Bespoke information available when needed with Complex clinical care provided by Admiral nurses (dubbed McMillan nurses for dementia).

Draft Expectation - By 2020, everyone person with a diagnosis of dementia will have a personalised care plan that is compliant with the quality standards assured by NCCMH and their families and carers will be able to say that the support they received met their needs. In addition, all health and social care professionals should have a basic understanding of dementia in line with the core competencies published by Health Education England, with information reported by CQC and NHS England

Living Well

“I feel included and I am treated with dignity and respect”

Rationale - This is a responsibility that goes way beyond health, there is an aspiration of four million dementia friends by 2020 to add to the one million already there, there are many examples around the country of dementia friendly cities, dementia friendly communities, dementia friendly schools, dementia friendly businesses which are enormously innovative it is that lived experience of dementia which is the hallmark here. Health Education England have recently published their core competencies

Draft Expectation - By 2020, every person with dementia should be able to say that their communities and organisations with whom they have contact treated them with dignity and respect. CCGs will support recruitment of dementia friends and the aspiration that every hospital will have signed up to John’s Campaign. Information on this should be published by CCGs, NHS England and NHS Improvement.

Dying Well

“I am confident my end of life wishes will be respected”

Rationale - One of the key challenges is that dementia is not always considered a terminal illness. There are a number of issues that are specific to dementia eg capacity but in general people living with dementia should be supported to die with dignity and respect in the place of their choosing.

Draft Expectation - By 2020: every person dying with dementia will have an Advanced Care Plan that has been managed according to the NICE End of Life Care Guidelines, monitored by CQC, CCGs and NHS England