DEMENTIA: IMPROVING TIMELY DIAGNOSIS

Introduction to the Dementia Prevalence Calculator v3
Introduction

In March 2012 the Prime Minister published his challenge on dementia\(^1\) which set out an ambitious programme of work to push further and faster in delivering major improvements in dementia care and research by 2015, building on the achievements of the National Dementia Strategy (2009)\(^2\). Central to the challenge is the requirement that from April 2013, there needs to be a quantified ambition for diagnosis rates across the country, underpinned by robust and affordable local plans (NHS Mandate, Department of Health)\(^3\).

The national dementia diagnosis rate is published annually through the NHS Information Centre and is contained within domain two of the NHS Outcomes Framework. The Dementia Prevalence Calculator Tool builds on this national methodology enabling local areas to account for local factors and establish estimates of their local prevalence rate, benchmark this with other groups, and establish improvement trajectories.

International experience would suggest that diagnosis rates of between 60 and 80 per cent are achievable and we expect that the 2012-13 England diagnosis rate \(^4\) of 47.47% can be substantially improved in future years. This guidance and the accompanying tool will help NHS Organisations to formulate ambitious plans and trajectories for improvement in order to deliver better dementia services for the future.

Whereas the need to improve recognition and diagnosis of dementia is not contested, there has been much debate about the meaningfulness of the data, and what ‘good’ looks like for the person with memory problems, for the GP who is often first point of call on a diagnosis pathway, for memory assessment services, and for their commissioners.

In 2012, the Department of Health commissioned NHS South of England to produce a new model for understanding prevalence. The aim was to improve the sensitivity, validity and meaningfulness of data about prevalence and diagnosis at the level of general practice and Clinical Commissioning Group; arrive at a better understanding what an upper threshold for diagnosis rate might be \(^5\); and to develop the means by which to project and set local ambitions for improvement.

The Dementia Prevalence Calculator (DPC) has been revised and updated for 2014-15. The DPC (v3) presents an opportunity for all health communities to gain a better understanding of their local estimated prevalence of dementia in the community, and among people living in local care homes. The tool enables General Practices and commissioners to establish a baseline by which to set and work toward local quantified ambitions for improvement in diagnosis rates, as set out in NHS Mandate, and inform local joint strategic planning, commissioning, and service redesign and improvement.
Support for commissioning dementia care

The DPC should be used in conjunction guidance, standards and other evidence produced by the National Institute for Health and Care Excellence (NICE).

Making commissioning decisions based on NICE guidance and standards and other NICE accredited evidence can help commissioners use their resources effectively to improve the quality of health and social care for people with dementia.

Commissioning dementia care in line with NICE guidance and standards should support commissioners to improve health and social care outcomes in line with the clinical commissioning group outcome indicator set and other national outcomes frameworks.

In particular, the DPC should be used in conjunction with the following NICE resources:

- NICE cost impact and commissioning assessment quality standard for dementia
- CMG48 NICE support for commissioners of dementia care
- QS1 Quality Standard for dementia
- QS30 Quality standard for supporting people to live well with dementia
- CG42 Dementia: Supporting people with dementia and their carers in health and social care
Dementia diagnosis resource pack

A dementia diagnosis resource pack has been produced to support commissioners and general practices to design and implement dementia diagnosis improvement plans. This is based on 10 key steps to improving diagnosis, and diagnosis pathways, and is accompanied by a range of resources, tools, and examples of innovation and positive practice.

The resource pack is available at the Dementia Partnerships knowledge portal http://dementiapartnerships.com/diagnosis/resource-pack/
Dementia Prevalence Calculator

DPCv3 is available via the Primary Care Web Tool at [https://www.primarycare.nhs.uk/](https://www.primarycare.nhs.uk/)

It is accessible to registered users including GP practice staff, CCGs, area and regional teams of NHS England and other approved stakeholder organisations.

This guidance supports the ‘User Acceptance Testing’ phase of development of the DPCv3. The calculator and full guidance will be released in March 2014.

To access DPCv3 click on the Register link at the top of the homepage. Complete the form on the 'register' page as per the screenshot below. A member of the Primary Care Web Tool team will get in touch. If you have any questions contact the Primary Care Web Tool Team primarycareweb@nhs.net.

![Register to Use the site](Image)

**INTRODUCTION: DEMENTIA PREVALENCE CALCULATOR v3**
To log in to DPCv3, enter your username (the email address that you registered with e.g. john.smith@nhs.net) and your password into the input boxes and click on the button labelled ‘Accept Terms and Conditions and Login’
Click on the domain labelled ‘medical’.

Click on the role labelled ‘Dementia Prevalence User’.
Use the navigation tools to view information about dementia prevalence, diagnosis rates and ‘diagnosis gap’ from 2009-10 to 2012-13 (most recent data) at the following levels:

- General Practice
- Clinical Commissioning Group
- NHSE Region
Click on the button labelled ‘Help’ for detailed guidance and instructions on using the calculator.

For enquiries during the ‘User Acceptance Testing’ phase of development of the DPCv3 please contact calculator@dementiapartnerships.com.

For enquiries about registration please contact the Primary Care Web Tool Team primarycareweb@nhs.net.
Dementia Prevalence Calculator (v3) - what it does

Using Dementia UK (2007) figures for prevalence of dementia, the calculator:

• applies these figures to a General Practice’s registered patient population, by age and by gender;

• in order to estimate local prevalence, the tool distinguishes between the patient population in the community, and those patients living in care homes;

• it considers prevalence at different phases of the disease (mild, moderate, severe), and by age group;

• it compares numbers on dementia registers with numbers of patients registered for co-morbid conditions, such as cardiovascular disease, in order to inform case finding;

• it aggregates general practice data at the level of Clinical Commissioning Group

• using prevalence data and the most recent Quality Outcomes Framework data (QOF DEM1), it allows the user to benchmark, and set trajectories for improvement in diagnosis rates;

• based on local trajectories for improvement, CCGs may determine a quantified ambition for improvement in its average diagnosis rate, year-on-year.

What this means for GPs and CCGs

The calculator will enable general practices and commissioners to,

• take into account estimated prevalence among the General Practice’s patients in local care homes, and in the community;

• review estimated local prevalence in relation to numbers of patients on the Practice’s dementia register, and estimate the Practice’s ‘diagnosis gap’;

• consider prevalence by age group, and by severity;

• use the data as a means of benchmarking progress to improve diagnosis rates, particularly in relation to sub groups (for example, patients with early onset dementia; patients with co-morbid conditions);

• take action to improve local diagnosis rates using a range of mechanisms, including improving coding, case finding, indicative screening, and education to improve recognition, assessment, and diagnosis.

Improvement plans

Templates for General Practice and CCG improvement plans, based on the '10 Key Steps' are available at http://dementiapartnerships.com/diagnosis.
## Definitions

The Dementia Prevalence Calculator uses the following definitions:

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td><strong>Prevalence</strong></td>
<td>The expected or predicted number of people with dementia.</td>
</tr>
<tr>
<td><strong>True or actual prevalence</strong></td>
<td>The number of people in the population who actually have dementia.</td>
</tr>
<tr>
<td><strong>Local prevalence</strong></td>
<td>The expected number of people with dementia in the local area, adjusted through the DPC Tool, weighted by number of care home places.</td>
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<tr>
<td><strong>Prevalence rate</strong>  or <strong>prevalence proportion:</strong></td>
<td>The expected or predicted prevalence as a % of population. This is point prevalence, i.e. the percentage of population with dementia at a point in time.</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td>The number of people detected in the population that have dementia. Diagnosis is the same as detection. (The number of people diagnosed with dementia is captured via the Department of Health Primary Care Quality and Outcomes Framework (DEM1).</td>
</tr>
<tr>
<td><strong>Diagnosis rate</strong></td>
<td>Diagnosis as a % of prevalence. This is the same as the detection rate.</td>
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<tr>
<td><strong>Diagnosis gap</strong></td>
<td>Prevalence rate minus diagnosis rate.</td>
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Further information

Dementia Prevalence Calculator v3 https://www.primarycare.nhs.uk

Dementia Partnerships knowledge portal: Improving timely diagnosis http://dementiapartnerships.com/diagnosis

Dementia diagnosis resource pack http://dementiapartnerships.com/diagnosis/resource-pack

References


4 The diagnosis rate is numbers of patients with a diagnosis of dementia, expressed as a percentage of the local estimated prevalence rate.

5 The Dementia Prevalence Calculator Project Steering Group, and Project Report (2012) concluded, and recommended that an upper threshold for maximum diagnosis rate should be in the range of 70-80%. This is also reflected in the World Alzheimer Report (2009).

6 This project uses the term ‘rate’ in the model, e.g. National Dementia Prevalence Rate (NDPR), reflecting vernacular description of percentages as rates. ‘Prevalence proportion’ is a more correct description.