

### Dementia Improvement Group

The Dementia Improvement Group met again at Taunton Racecourse on 4<sup>th</sup> June. There was an unprecedented turnout of enthusiastic and committed stakeholders, suggesting that engagement with the dementia challenge continues to grow in the South West and the DIG is a popular and useful forum for sharing best practice, knowledge and ideas. Thank you to everyone who made arrangements to attend.

### Diagnosis rates

Latest diagnosis rates released by HSCIC from March 2015 prevalence data shows a marked increase in the South West compared to August last year (in brackets):

England overall	60.8% (53.3%)
South of England	57.6% (49.9%)
<b>South West</b>	<b>57.5% (51.3%)</b>
South Central	57.4% (52.8%)
South East	56.1% (48.7%)

Nick Cartmell informed the group that HSCIC should next release fresh diagnosis rates in July. Importantly, these will use a different - more accurate and UK evidence-based - calculation method. The UK evidence, from the CFAS II study,

suggests that the true prevalence of dementia in many parts of the UK is actually significantly lower than that used in diagnosis rate calculations to date.

Therefore it is anticipated that most CCGs will see a rise in diagnosis rates when fresh data is calculated using the new method.

Nick warned commissioners and NHSE against trying to produce their own diagnosis rate figures ahead of HSCIC because of the increased complexity of the new calculation method. Ultimately we will all be compared and judged on HSCIC data, not other data, so we must be patient and wait for that to be released.

Looking ahead we have a new Government but the same Secretary of State so we may expect diagnosis rates to remain a priority for NHS England who are continuing to put pressure on CCGs who have large populations and are currently falling short of the 66.7% target.

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## Young Onset Dementia Working Group

This Group was set up to ensure younger people diagnosed with dementia in the South West receive best practice information, support and care. The group met in March and discussed how the support of adults of working age with dementia has some unique features that are different from later onset dementia but also has many needs in common.

Hilary Doxford, who has dementia but continues to work, made a case for compiling a registry to allow better information about prognosis. If anyone is able to help progress this suggestion please make contact with the SCN as below.

In order to provide guidance to commissioners, providers, social care and voluntary sector, the SCN is undertaking a mapping exercise of service provision in the region for those with Young Onset Dementia and will circulate the mapping exercise results to the wider DIG once collated. This may then be compared to services elsewhere in the UK (e.g. Cardiff and Oxford), and what is being provided through specialist commissioning (e.g. for people with Huntington's Disease). The desired outcome is to identify where special services for people with unique needs might sit (e.g. adult mental health or neuropsychiatry or neurology) and how they should be commissioned so that development of such services can proceed in the region.

Members of the DIG agreed that there is a great appetite for this Working Group, but further thought is needed on its name to reflect that the Group is focussing on the unique needs of some people with dementia, irrespective of whether they are still working or young, that are not catered for by standard dementia services.

If anyone wishes to join the young onset dementia group please email [Marianna.moors@nhs.net](mailto:Marianna.moors@nhs.net).

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## Dementia Risk Reduction

This is now a Public Health England priority and there will be a national media publicity campaign in January 2016 - "Live Well" - aimed specifically but not exclusively at the middle to low socio-economic members of the population. The campaign will highlight the benefits of lifestyle improvements in middle age, one of which is delaying or avoiding dementia in older age.

Nick Cartmell called on NHS commissioners to work closely with local Public Health, Local Authority and Health & Wellbeing Boards to develop their own dementia risk reduction strategy and harness the opportunity provided by the national campaign to promote local services for people with dementia and lifestyle improvement resources.

This approach is now being supported by a regional Public Health-led Dementia Risk Reduction Working Group led by Dr Pamela Akerman in Bristol which is

designed to link strongly with the SCN DIG.

Furthermore NICE should shortly be publishing dementia risk reduction guidelines which detail which organisations should be responsible for delivering each aspect of a joined-up strategy.

However, Dr David Llewellyn from Exeter University stressed that public awareness-raising or vague slogans would not by itself deliver the risk reduction demonstrated in international research: there is also a need for each local area to develop a structured lifestyle change service which supports individuals to make realistic behaviour changes. He also recommended harnessing modern technology opportunities to track progress e.g. the use of mobile phone apps and online personal change logs.

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### Enhancing Care Home Support

Tammy Jones, Project Lead from The South Devon Dementia Learning Community, presented their care home project which recently won the BMJ award for Dementia Team 2015.

Devon Partnership Trust and Plymouth University undertook work in care homes in the Torbay area, where dementia champions worked to improve knowledge, leadership, skills and confidence among care home staff. Tammy spoke about the changes that have been achieved in care homes, including memory boxes,

meaningful activities, improving choice and mealtime experiences and life story work.

Formal evaluation of the project is expected in July 2015 and a local conference is being held on 23<sup>rd</sup> July 2015 to celebrate the project's success.

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### Barbara's Story

Helen Vaughan, Joint Commissioning Manager for Dementia at NHS Gloucestershire CCG, and Sarah Warne, Head of Safeguarding (Adults and Children) for Gloucestershire Care Services NHS Trust, presented Barbara's story, a series of short films which have been developed as a dementia awareness resource by Guy's and St Thomas' NHS Foundation Trust around the needs of people with dementia in hospital.

Barbara's Story aims to encourage hospital staff to think about the small things that could make a difference to the care of an older person which might go beyond their job description, and is directed at both clinical and non-clinical staff.

There are 6 episodes in total plus a range of supporting resources, and the package is designed to be shown to staff as facilitated sessions. The package is available free from

[eileen.sills@gstt.nhs.uk](mailto:eileen.sills@gstt.nhs.uk).

To watch Barbara's story, follow this link:

<https://www.youtube.com/watch?v=VFXirEnjftI>

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## Dementia Health Fairs in the South West

Sue Greenwood, Clinical Lead for Dementia for Plymouth Community Healthcare, updated the Group on health fairs they are hosting in partnership with the League of Friends and Alzheimer's Society. These health fairs provide a place for support and advice for carers and people with dementia and also allow the gathering of feedback on how services might be improved in community hospitals and the community in general, and how well the Dementia CQUIN is being achieved.

The next health fair will be held in Wadebridge Town Hall on Monday 14<sup>th</sup> September 2015, 2-4pm. All welcome.

For more information please email Sue Greenwood direct:  
[Sue.Greenwood2@pch-cic.nhs.uk](mailto:Sue.Greenwood2@pch-cic.nhs.uk)

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## Join Dementia Research

Alexandra Hodges, Join Dementia research Project Officer, presented Join Dementia Research. This initiative is a collaboration between the National Institute for Health Research, Alzheimer's Society, Alzheimer's Research UK and Alzheimer's Scotland. It is funded by the Department of Health and is designed to help people with dementia, and their carers, to get involved in research (and enjoy the potential benefits) by adding their details to a new national dementia research register.

People on the register may then be approached by new or ongoing dementia research projects to invite participation without any obligation.

For more information, including online registration for interested people, please visit [www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk).

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## Dementia Diagnosis Decision Support

Dr David Llewellyn from the University of Exeter presented DECODE, a computerised decision support system for the timely identification of dementia. Aimed primarily at General Practice, in response to growing emphasis on GP diagnosis *without* referral to specialist, DECODE fine-tunes an individual patient's chances of having dementia as more information is added to the system, for example the patient's age, brief cognitive test score, risk factors.

It is a similar concept to the widely used Qrisk cardiovascular risk prediction tool and Macmillan risk prediction tools for some cancers. DECODE offers a significant reduction in the risk of mis-diagnosis - both people wrongly diagnosed with dementia who don't have it, and those reassured they don't have it who actually do - compared to the risk of mis-diagnosis associated with using brief cognitive assessments and unstructured history-taking alone.

A workshop to explain DECODE to healthcare professionals is planned on

Wednesday 30<sup>th</sup> September, 9am – 5pm at the University of Exeter.

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## Membership

The Dementia Improvement Group welcomes stakeholders from the following sectors:

- primary care, particularly CCG leads
- specialist older person's mental health services
- older person's acute care social care commissioners
- voluntary sector providers
- representatives of the needs and views of people with dementia and their carers and families
- carers
- research networks
- post-graduate medical education
- Strategic Health Authority
- public health
- National Institute for Creative Ageing.

The main quality expected of Group members is the possession of great enthusiasm for improving anything which relates to dementia in the South West (see map). This might be through one of the "three Ps": Power (being able to implement change), Pounds (having access to resources to support change) or Passion (enthusing others to embrace change).

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## Contacts

For up to date information about the work of the Dementia Network please go to [www.swscn.org.uk](http://www.swscn.org.uk) or [www.dementiapartnerships.org.uk](http://www.dementiapartnerships.org.uk).

To publicise any examples of positive practice in the South West, or to offer feedback on any technical or accuracy aspects of the content of this website please send an email to [rowan@dementiapartnerships.org.uk](mailto:rowan@dementiapartnerships.org.uk).

To discuss any aspects of the work of the SCN and DIG, please contact our network manager Justine Faulkner at [justine.faulkner@nhs.net](mailto:justine.faulkner@nhs.net).