

## **SLOUGH BOROUGH COUNCIL**

**REPORT TO:** Health Scrutiny Panel    **DATE:** 21<sup>st</sup> November 2013

**CONTACT OFFICER:** Alan Sinclair  
Assistant Director Adult Social Care, Commissioning and  
Partnerships  
01753 875752

Sangeeta Saran  
Head of Operations, Slough CCG  
01753 636572

Susanna Yeoman  
Head of Mental Health Services (SBC) / Deputy Locality  
Director (BHFT)  
01753 635663

**WARD(S):** All

### **DEMENTIA CARE STRATEGY: A PROGRESS UPDATE**

#### **PART I**

#### **FOR INFORMATION**

1.    **Purpose of Report**

To provide an update to the Committee on the implementation of the Dementia Strategy for Slough.

2.    **Recommendation(s)/Proposed Action**

The Committee is requested to note the report.

3.    **The Slough Joint Wellbeing Strategy, the JSNA and the Corporate Plan**

This update report on Dementia Care Strategy in Slough links directly to the Health priority contained within the Joint Wellbeing Strategy 2013-16:

‘A growing number of older people will suffer from dementia in Slough. Slough’s demand for dementia services is growing, and will continue to do so for the foreseeable future’.

A priority action of Slough’s Joint Wellbeing Strategy is to implement the National Dementia Challenge.

The themes in this report also link to the Wellbeing Strategy ‘Safer Slough’ priority, with multi-agency partners working together and with patients and families, to ensure that people with dementia are effectively safeguarded and treated with dignity and respect.

Cross cutting themes

Residents can take up offers of health screening and support family members in high risk groups to do so. Residents can also benefit from opportunities described in this report, to learn how to manage dementia related conditions, and access support available.

The image of Slough can be improved and the experience of residents and carers with dementia can be enhanced, by the developments aiming to promote ‘dementia friendly communities’ which are described in this report.

Slough JSNA 2013 identifies increasing projected incidence of dementia, both in under 65 years and older 65 years age groups. The JSNA identifies opportunities to extend the work of dementia advisers across East Berkshire, and describes an opportunity to develop a psychiatric liaison project following the exemplar RAID model (Rapid Assessment, Interface and Discharge) to improve outcomes and reduce length of stay for patients with dementia and mental health problems admitted to acute hospitals.

4. **Other Implications**

(a) Financial

An increase in numbers of people with dementia living in Slough will give rise to a financial impact, which will need to be managed by Slough Borough Council and Slough Clinical Commissioning Group. During 2012 and 2013, additional investment was made through the Slough Clinical Commissioning Group and South East England Innovation fund, and has been used to improve the pathway for early diagnosis, and for targeted projects.

(b) Risk Management

<b>Recommendation</b>	<b>Risk/Threat/Opportunity</b>	<b>Mitigation(s)</b>
Implementation of the National Dementia Strategy in Slough	<p>Increasing prevalence and demand could result in insufficient capacity within services.</p> <p>Council and health service budget constraints could result in services being under-resourced.</p>	<p>Services have received investment from CCG to increase memory clinic capacity. Options to extend Liaison service are being explored.</p> <p>Joint working with multi-agency partnerships including voluntary and third sector are being pursued to implement the strategy.</p>

	Dementia adviser post has only been funded on fixed term until March 2014	Options are being explored to create a permanent funded post.
--	---	---

(c) Human Rights Act and Other Legal Implications

There are no Human Rights Act or other legal implications associated with this report.

(d) Equalities Impact Assessment

There is no Equalities Impact Assessment as this update does not include new or revised policy, procedure or function. Equalities information (gender, age ethnicity) is included within the report for information.

(e) Workforce

Workforce implications relate to training of Council and other workers within Slough, including 'awareness raising' for local businesses.

5. **Supporting Information**

**5.1 Key National Documents**

National Dementia Strategy 2009-2014

The 5 year national strategy 'Living Well with Dementia' was published in 2009 and contains a vision for transforming dementia services, in order to achieve better awareness of dementia, early diagnosis and high quality treatment at whatever stage of the illness and in whatever setting. The strategy contains 17 objectives which are summarised in Appendix A.

Prime Ministers Dementia Challenge 2012

The Dementia Challenge was launched in March 2012, by Prime Minister David Cameron, identifying dementia as 'one of the most important issues we face as the population ages'. It is a programme designed to make a qualitative difference to the lives of people with dementia and their families and carers, building on progress made through the National Dementia Strategy. There are 3 main areas for action: driving improvements in health and care (improve rates of diagnosis, diagnosis pathway, experience of people receiving a diagnosis and post-diagnosis support), create dementia friendly communities and improve dementia research.

**5.2 Slough's Dementia Strategy Implementation plan.**

A multi-agency group was formed in Slough, following publication of the National Dementia Strategy 2009. The purpose was to oversee implementation of the 17 strategy objectives in line with East Berkshire Joint Commissioning Dementia Plan and Joint Strategic Needs Assessment.

During 2012, an exercise was undertaken to compare Slough's performance against each of the National Dementia Strategy objectives. From this exercise, achievements and gaps were highlighted (summarised in Appendix A).

Achievements were noted as follows:

- There is good engagement in the group from multi-agency partners, including statutory health and social care services, housing, and voluntary sector, with a nominated GP representative.
- Memory services are well established and have been enhanced through Berkshire Healthcare NHS Foundation Trust (BHFT) re-organisation. In 2012/13 and 2013/14 additional CCG investment in memory services has allowed further expansion of Slough's memory services.
- Information and advice sessions, and Alzheimer cafes for public, service users and carers have been established in partnership between statutory and secondary care services.
- An East Berkshire Older Persons Mental Health Liaison service has been commissioned since 2012 and this service was further enhanced with a part time psychiatrist from 2013. Heatherwood and Wexham Park Hospitals (HWPH) have created a team of three registered mental health nurses to work with in-patients with mental health needs, largely dementia.
- A national dementia CQUIN (Commissioning for Quality and Innovation) payment was introduced in 2012 within HWPH and BHFT (in-patients) to aid early detection of dementia.
- Funding was identified through Winter Pressure resources for a Dementia Adviser post for one year from September 2012 and this has now been extended to March 2014.
- End of Life services are engaged as part of the multi-agency partnership considering dementia care.
- Information regarding training and information materials has been shared between all agencies.
- In 2012 Slough was successful in partnership with Royal Borough of Windsor and Maidenhead and Bracknell Forest Council, in securing funding for two projects through the South of England Innovation Fund. The projects are for Dementia Directories and Dementia Friendly Communities

Areas for further action were noted as follows:

- Diagnosis pathway required 'refresh', in particular referral routes and the interface between primary and secondary care.
- Data projections for Slough needed to be better understood.
- Diagnosis rates: data for Slough showed that we have a significant 'dementia gap' with only one-third of the expected numbers of people in Slough having a formal diagnosis of dementia. Data showing numbers diagnosed in Slough was believed to be inaccurate and incomplete.
- We did not have data indicating numbers of people from Black, Asian and Minority ethnic groups diagnosed or engaging with services.
- People with learning disability who may be at particular risk of developing dementia were not being identified.

- Access to information and support for carers and service users could be inconsistent.
- Public awareness needed to be increased.
- Access to suitable housing and assistive technology (telecare) options for people to remain in their own homes was not well established.

As a result an action plan was identified to address gaps against each of the above areas. The following sections describe each area and associated actions in more detail.

### **5.3 Diagnosis and treatment pathway**

Benefits of early and accurate diagnosis are well documented. These can include greater benefit from anti dementia treatments and psychological therapy, as well as opportunities to plan for the future, consider advance decisions and gather information about the condition.

The diagnosis pathway in Slough has now been refreshed and includes the following elements:

- Primary care screening
- Referral to memory clinic
- Memory clinic treatment and interventions
- Onward referral to appropriate services (social care, voluntary and third sector services)
- Carer assessment and support

#### Anti-psychotic medication

Over-prescribing of anti-psychotic medication for people with dementia is a national concern. A local register is maintained by BHFT memory service, of known dementia patients who are being prescribed anti-psychotics, and their treatment is regularly reviewed. GPs and care homes are supported to consider alternatives to medication for people with dementia who may have challenging behaviours, in line with guidance produced by the Alzheimer's Society.

#### Patients of Heatherwood and Wexham Park Hospital

Patients under acute hospital care (HWPH) are identified for memory screening and referral. This is done via the Acute Trust, whereby the mental health nurses offer a screening for patients age 75+ with memory problems, undertake a risk assessment and referral to GP or liaison team.

The BHFT mental health liaison psychiatry service undertake full assessment, make diagnosis and advise acute trust colleagues on dementia treatments whilst the patient is under acute trust care.

Key steps for CCG commissioning groups and Primary Care in the dementia pathway are summarised below:



#### 5.4 Data projections for Slough

A review of data projections has been undertaken, aiming to establish current prevalence data and projections, and triangulate data from POPPI, (Projecting Older People Population Information), Slough memory clinic, and GP dementia registers. Gathering this information will enable us to assess the extent to which current services are meeting our local projected demand. Accurate data projections will be used to inform service reviews and planning, and commissioning strategies.

Across the whole of the UK, records indicate that there is a low rate of dementia diagnosis compared to expected numbers. The percentage of people with dementia who have a diagnosis, rose from 43% in 2010, to 46% in 2012. Diagnosis rates in South of England are the lowest in the country.

The data for Berkshire East shows that in 2011, 34.6% of people with dementia had a diagnosis, rising to 39.9% in 2012.

*(Mapping the Dementia Gap, Alzheimers Society).*

Figures for Slough Clinical Commissioning Group 2011-12 are available from the National Dementia Prevalence Calculator, and indicate that based on adjusted national prevalence figures (GP population profile), 919 people in Slough would be expected to have a diagnosis of dementia. Of these, 233 will be in care homes.

POPPI data projections show a similar picture. In 2012, the total number of people age over 65 years in Slough with dementia is expected to be 963, rising to 1221 in 2020. Detailed tables with breakdown by age group and gender are provided at Appendix B.

The prevalence of dementia is set to increase steadily between now and 2030. Because of our younger population profile in Slough, numbers are increasing less rapidly than in neighbouring authorities.

Additional investment has been made by Slough CCG in 2012/13 and 2013/14, to increase capacity in memory services in line with increasing demand.

### 5.5. Numbers of Slough Residents with a Dementia Diagnosis

Ascertaining the actual number of people diagnosed with dementia in Slough is problematic. The number of cases on General Practice Quality and Outcomes Framework (QOF) dementia registers is usually taken as the measure. For 2011-12, the QOF register indicates 329 named individuals for Slough with a diagnosis of dementia.

Using modelled projections described above, this suggests a diagnosis rate of around 36.6%, and a shortfall of approximately 570 undiagnosed Slough residents. This compares with 43% in WAM and 37.8% in Bracknell and Ascot CCG areas, and suggests that Slough has the lowest diagnosis rate in East Berkshire.

However, we now know that GP registers may not be reliable for the following reasons:

- The registers are dependent on General practices entering the patients diagnosis onto the register.
- QOF figures have not been refreshed since 2011-12.
- Quality and Outcomes Framework data has moved across to a new system (Calculating Quality Reporting Service) which is not yet 'live'. There is therefore currently no means to ascertain whether the figure of 329 for 11-12 has increased.

Slough memory service delivers a monthly report on current numbers of open cases. For August 2013, the 'snapshot' figure was 381. RIO (the NHS database system) data indicates at least 465 Slough patients have been diagnosed in the past two years.

Dementia Diagnosed Qtr2 Month 5										
Age Band	Under 65		65-75		76-85		Over 85		Grand Total	% Dementia /Caseload
Locality	F	M	F	M	F	M	F	M		
Slough	4	8	26	34	104	70	95	40	381	62.15%

This demonstrates that the GP dementia registers are inaccurate, under-representing the total numbers diagnosed. However it is not clear what the total numbers and 'dementia gap' are for Slough.

In order to address this, GPs have been asked to ensure registers are fully updated, and all correspondence from memory services prompts them to do so.

As a result of these efforts, the percentage of people recorded as having a diagnosis should have increased significantly when the new system begins reporting (scheduled for January). The target set by the Dementia Challenge 2012 is to increase diagnosis rate to 60% by 2014/15 of the estimated local prevalence.

### Young onset dementia

Projecting Adult Needs and Service Information (PANSI) figures show the following projection for Slough of numbers expected to have 'young onset' dementia (aged under 65 years):

	2012	2014	2016	2018	2020
Total males age 30-64 predicted to have early onset dementia	17	18	18	19	20
Total females age 30-64 predicted to have early onset dementia	12	12	13	13	14

Pansi.org.uk November 2013

Younger people with dementia and their carers can be at risk of 'falling through the net' of health and social care services. Research shows they can be subject to delays in diagnosis, poor after-care and a lack of age-appropriate services. The National Dementia Strategy outlines that the needs of younger people with dementia may be different from the majority of the population with dementia, and require specifically tailored approaches. Younger people with dementia are generally referred and supported by community mental health services, and a business case is being developed for proposed specialist service delivery across Berkshire.

The above caseload snapshot for Slough shows only 12 people under age 65 diagnosed with dementia and currently open to memory services. PANSI projections suggest that there could be a 'gap' in the region of 17 people in Slough undiagnosed in this age group.

### **5.6 Dementia and Ethnicity**

Numbers of people with dementia from Black, Asian and Minority Ethnic (BAME) groups in England and Wales are likely to rise significantly faster than the rest of



the population, as people who moved here between the 1950s and 1970s are reaching their 70s and 80s. Despite this increase, Black, Asian and Minority Ethnic people are generally under-represented in dementia services

However, snapshot data indicates that this is not the case in Slough, and that BAME populations have engaged with dementia services.

*Snapshot data (Jan- March 2013) of memory clinic patients with dementia diagnosis compared with population figures for over 65years:*

	Asian	Black	Mixed	White (British, Irish) and white other	Other ethnic group	Not stated	Total
Slough memory clinic caseload	17%	3%	1%	67%	3%	9%	100%
Slough over 65's general population (POPPI)	16%	5%	0%	79%	0%		100%

The needs of BAME patients can be complex and can require specialist interpreting and a culturally sensitive approach. Slough mental health service is due to employ a BAME Support Worker as a pilot project which will be evaluated in March 2014.

### **5.7 Dementia services for people with learning disability**

People with learning disability, and in particular, people with Downs Syndrome, are at higher risk of developing younger onset dementia. There are particular difficulties in achieving accurate dementia diagnosis and early treatment with this group.

Numbers of people with Down's syndrome who have Alzheimer's disease are approximately:

- 1 in 50 of those aged 30 to 39 years
- 1 in 10 of those aged 40 to 49 years
- 1 in 3 of those aged 50 to 59 years
- More than half of those who live to 60 or over.

*(Alzheimers society website)*

Studies also indicate that the numbers of people with learning disabilities other than Down's Syndrome who have dementia, are approximately three to four times higher than in the general population.

Actions have been undertaken in Slough

- to create a streamlined pathway for people with a learning disability to access diagnosis and treatment
- to enable those at high risk of early onset dementia to be identified and provided appropriate screening
- to ensure appropriate information and support is available

A local database has been established to identify those at particular risk. This includes people over age 30years with Downs Syndrome, and people over age 60 years with other learning disability.

The register records 41 service users age 30+ in Slough with Downs Syndrome, and 12 service users with other learning disability age over 60years. Effective diagnosis of dementia depends upon baseline measures being carried out, and the database has enabled this to be undertaken in a proportion of cases, with plans for screening to be undertaken in all new cases.

Currently 5 Slough residents with Downs Syndrome have been diagnosed with dementia and are being provided with treatment.

## **5.8 Information, Advice and Support for Service Users and Carers**

The National Dementia Strategy highlights the importance of appropriate information being made available to service users and carers, in particular for appropriate information to be made available at different stages of the patient's journey.

Actions are in train to achieve this in Slough. The two key areas of development in this area are as follows:

### Dementia advisor

This is a new role introduced in Slough in September 2012. The function of the dementia advisor is to provide a consistent relationship, offering personalised and responsive practical support. The focus is on individual empowerment to access the information and support needed, promoting independence, self-help, well-being, choice and control.

The National Dementia Challenge recognises the enormity of the impact on carers and recommends that carers' needs should be given parity with those of the person diagnosed with dementia. The dementia advisor also has a role as carer champion, ensuring that carers receive timely flexible advice, information, and personalised support to undertake caring roles.

Within the first 6 months, 62 referrals were made to the dementia adviser through the Slough memory clinic. Feedback from service users and families is that the worker has made a significant impact in easing the stress of dealing with the diagnosis and signposting to appropriate support.

## Dementia Directories

In 2012, in partnership with Bracknell Forest Council and the Royal Borough of Windsor and Maidenhead, Slough Borough Council submitted a bid for 'Dementia Challenge' funding released through the South of England Innovation fund.

The East Berkshire partnership was successful in its bid, and was awarded funding to develop Dementia Directories. The Slough bid included funding to address issues of the diverse and multi-lingual population as well as general directory information. The project is focussing on updating and improving Slough Borough Council's web based directory.

### **5.9 Raising Public Awareness: 'Dementia Friendly Communities'**

A 'Dementia Friendly Community' is a 'city, town or village where people with dementia are understood, respected, supported, and confident they can contribute to community life' (Prime Ministers Dementia Challenge, 2012). The approach promotes the involvement of local businesses, charities, independent, voluntary and community services, as well as the statutory sector.

In Slough, a further sum awarded through the Dementia Challenge fund is being used to commission a training supplier to deliver a programme of training. This has been tailored to different audiences, including the health and social care workforce, statutory and voluntary sector, and local businesses. A list of 100 target businesses and services is being drawn up, including Slough Borough Council 'public facing' services such as leisure centres, and business such as Tesco and Mars. Safeguarding adults information is being included alongside dementia awareness information, and the training will be delivered between November 2013 and January 2014.

The anticipated outcomes will be to raise awareness in local communities, and challenge stigma, as well as to inform services and local organisations of the small things they can do to make their services 'dementia friendly'. This workstream builds on a previous project to establish a 'safe place' scheme in Slough.

The concept of 'Dementia Friendly Communities' extends to acute and community hospitals. Wexham Park Hospital has invested in improving the environment for patients with dementia, with a dedicated 'Sunflower lounge', and undertaken extensive training for clinical and support staff.

### **5.10 Housing and Assistive Technology**

The Department of Communities and Local Governments '*More Choice, Greater Voice*' publication provides a toolkit as an aid for strategies in calculating the provision of accommodation and care for older people.

		<b>Suggested levels of provision per 1,000 of the population aged 75+</b>	<b>Provision for Slough based on population demographics at 2012</b>	<b>Currently in Slough</b>	<b>Suggested provision by 2020</b>	<b>Suggested provision by 2030</b>
<b>Extra Care Housing</b>	<b>For rent</b>	<b>12.5</b>	<b>79</b>	<b>106</b>	<b>91</b>	<b>128</b>
	<b>For sale</b>	<b>12.5</b>	<b>79</b>	<b>20</b>	<b>91</b>	<b>128</b>
<b>Housing based on provision for dementia</b>		<b>10</b>	<b>63</b>	<b>?</b>	<b>73</b>	<b>102</b>

Slough Borough Council is developing an Extra Care Housing strategy to take account of the needs of people with dementia. In addition, the Older Persons Commissioning Strategy identifies as a priority, the development of appropriate housing and telecare, and includes investment in telecare, including assistive technology solutions for dementia.

#### 8. **Appendices Attached**

- 'A' National Dementia Strategy 2009-2014: a summary of the strategy objectives.
- 'B' POPPI projections November 2013  
(Projecting Older People Population Information)

#### 9. **Background Papers**

None