



Ipswich and East Suffolk  
Clinical Commissioning Group



# **REDESIGNING DEMENTIA SERVICES**

## **REPORT OF THE CONSULTATION WORKSHOP OF 26 FEBRUARY 2013**

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# DEMENTIA CONSULTATION WORKSHOP

## 1. INTRODUCTION

### **Dementia**

Dementia is a progressive and largely irreversible clinical syndrome that is characterised by a widespread impairment of mental function. Although many people with dementia retain positive personality traits and personal attributes, as their condition progresses they can experience some or all of the following: memory loss, language impairment, disorientation, changes in personality, difficulties with activities of daily living, self-neglect, psychiatric symptoms (for example, apathy, depression or psychosis) and out-of-character behaviour (for example, aggression, sleep disturbance or disinhibited sexual behaviour, although the latter is not typically the presenting feature of dementia).

The aims of treatment, care and support are to promote independence, maintain function and treat symptoms including cognitive, non-cognitive (hallucinations, delusions, anxiety, marked agitation and associated aggressive behaviour), behavioural and psychological symptoms.

Dementia is associated with complex needs and, especially in the later stages, high levels of dependency and morbidity. These care needs often challenge the skills and capacity of carers and services. As the condition progresses, people with dementia can present carers and social care staff with complex problems including aggressive behaviour, restlessness and wandering, eating problems, incontinence, delusions and hallucinations, and mobility difficulties that can lead to falls and fractures. The impact of dementia on an individual may be compounded by personal circumstances such as changes in financial status and accommodation or bereavement. (*Dementia Quality Standard 1, NICE, June 2010*)

Ipswich and East Suffolk has an ageing population with 73,348 (19%) of its population of 385,000 aged over 65. The incidence of dementia rises with age and there has been increased demand for dementia diagnosis at the Memory Clinic, and the Community Mental Health Teams. This increase has also been reported by the Hospital Psychiatric Liaison Service at Ipswich and East Suffolk, the Dementia Intensive Support Service, the Flexible Dementia Services and in other services provided by both statutory and third sector. Post diagnostic services are provided by Suffolk Social Services, Primary Care, by Norfolk and Suffolk Foundation Trust, Suffolk Community Healthcare and the voluntary and community sectors. Whether these services are adequate and appropriate was the focus of the consultation.

### **The Case for Service Redesign**

The drivers for service redesign are a need to improve the current diagnosis rate from 42% to 75% of people with dementia. There is also a growing understanding that the current situation leaves people unsupported for too long and as a consequence there is over-reliance on expensive crisis response services. Suffolk has an increasingly ageing population; two thirds of people with dementia live in their own homes, one third live in care homes. At least two thirds of people living in care homes have some form of dementia. Populations living in rural areas experience difficulties in accessing centralised services because of transport links and the need for carers to escort patients to clinics. The situation has forced the CCG to assess current capacity and appropriateness of services against the inevitable rise in future demand. Rurality has an impact on health inequalities of people with dementia. People over the age of 65 tend to have age related physical and sensory difficulties that can restrict their ability to access the Memory Service at Ipswich Hospital many miles away from where they live.

## PREVALENCE ESTIMATES OF DEMENTIA IN IPSWICH AND EAST SUFFOLK

Age Group	Ipswich	East Suffolk	Total	Estimated Dementia Prevalence
30-64			7,700	105
65-74	12,608	24,952	37,560	778
75-84	9,125	15,952	25,077	2189
85+	3,691	7,020	10,711	2670
<b>TOTAL</b>	25,424	47,924	73,348	<b>5742</b>

Source: Public Health Profile, Ipswich and East Suffolk CCG, March 2012, S Patterson, Public Health

### Capacity to Diagnose Dementia

The NHS England *Dementia Prevalence Calculator* has current diagnosis at 42% of people living with dementia in Ipswich and East Suffolk. 55% of people with dementia are in the mild stages of the condition, 32% are moderate and 13% are severely affected. The main target for the redesigned Memory service is to increase diagnosis of people with mild dementia. With appropriate investment, the ambition is to increase diagnosis to 75% by 2016.

The Memory Clinic operates Monday to Friday with 1 full time Associate Specialist and 1 part time Consultant, 2 full time nurses and 2 full time administrators. The clinic has a few hours from a clinical psychologist and a pharmacist who is also a non-medical prescriber. The nurses see people in their home environment for medical follow up or initial assessment. The clinic sees about 50 patients a month (up to 600 patients a year). The current Memory Service would be unable to meet the increase in diagnosis from 42% to 75% without additional capacity.

There are 3 Later Life Community Mental Health Teams (CMHTs) across the Coastal, Central and Ipswich areas who see on average 2000 people a year, of which 1273 in 2012 were dementia diagnosis patients.

### Post Diagnosis Service Provision

The commonly held view is that once diagnosed, dementia patients are discharged into the community to cope until they are in crisis, their condition having deteriorated. Many statutory and voluntary agencies provide support services for people with dementia in the community. However, patients and their carers do not effectively access support services, either because they do not know or understand them; some services are experienced as inflexible or unsuitable and a number of services seem to provide much the same thing.

CMHTs estimate that 25% of patients seen at the Memory Clinic are subsequently referred to the CMHT within 6 months and 85% referred to the CMHT within 12 months of diagnosis, with concerns about memory or behaviour deterioration and unable to cope. Much of this would be curtailed if patients could access more post dementia support. GPs in primary care need information about post diagnosis services. Generally services are fragmented and not cohesive. In summary there are gaps in information about the services and gaps in the range, appropriateness and quality of services available.

A Dementia Advisor service was commissioned in 2012 to address this situation so that people can be connected with support mechanisms following a diagnosis of dementia. The Dementia Telephone Helpline equally can channel people toward networks of support. It is clear too that there needs to be more co-ordination and commissioning of post diagnosis support services.

NICE Clinical Guideline No. 42 prescribes pharmacological interventions for people with cognitive symptoms of Alzheimer's disease.

- Only specialists in the care of patients with dementia (psychiatrists including those specialising in learning disability, neurologists and physicians specialising in the care of older people) should initiate treatment. Carers' views on the patient's conditions at baseline should be sought.
- Treatment should be continued only when it is considered to be having a worthwhile effect on cognitive, global, functional or behavioural symptoms.
- Patients who continue on treatment should be reviewed regularly using cognitive, global, functional and behavioural assessment.

Any redesigned service in the community would be consultant led and NICE compliant.

### **Aims of Redesigning Dementia Services**

1. To increase dementia diagnosis from 42% to 75% by 2015/16
2. To develop more comprehensive, cohesive and integrated services across the dementia care pathway, providing services near to where people live.
3. To ensure an effective response to the needs of people affected by dementia

## **2. THE CONSULTATION PROCESS**

The workshop was one of three methods used to secure the views of those who work closely with dementia in Ipswich and East Suffolk CCG.

- 2.1 A **clinical scoping exercise** was undertaken on the 11 December 2012 involving professionals from the Memory Clinic, Adult and Community Services and Ipswich and East Suffolk CCG. The capacity to diagnose increasing dementia cases was a recurring theme as was the need for more post diagnosis services in the community. The findings of scoping influenced this subsequent more comprehensive workshop of 26 February.
- 2.2 The **dementia consultation workshop** of Tuesday 26 February aimed to gather in depth views from a wider range of people who provide frontline dementia services. Fifty-two people attended the event, including representatives from community organisations, the voluntary sector, home care agencies, people from nursing and residential care homes, Suffolk County Council, NSFT, Ipswich Hospital, GPs and staff from Ipswich and East Suffolk CCG. Each workshop table had a balance of people from each sector. The tables considered dementia diagnosis, post diagnosis care provision and what people considered a successful dementia service would look like (see Appendix I and II). This report is a product of their discussions and will inform the redesign process.
- 2.3 **Engaging GPs in Discussions about Diagnosis in Primary Care**  
The CCG Dementia Lead sent a letter to all GPs (Appendix VI) informing them of the need for a more sustainable dementia services. The letter asked GPs to *express an interest* in being one of 10 practices that might offer a diagnostic service in their locality. Of the 41 GP practices in Ipswich and East Suffolk CCG, 20 - just under 50% - have expressed an interest in taking part in the initiative.
- 2.4 On Wednesday the 27 February, there was a **GP Education Event** run by the CCG Commissioning Implementation Team. This provided an opportunity to consult over 150 General Practitioners (in groups of approximately 25) about the proposed redesign of dementia services, especially their views about the proposed increase of dementia diagnosis in primary care. A write up of their responses is at Appendix VI.

- 2.5 Evidence from the consultations above would indicate general agreement that dementia services require redesign to increase capacity to meet the growing numbers of people diagnosed with dementia. The workshop results also recognise that that post diagnosis services are fragmented and would benefit from more cohesion, joint planning and joint commissioning.

### **3.0 THE WORKSHOP AND ITS FINDINGS**

The workshop agenda and attendance list is at Appendix I and II.

#### **The Workshop Facilitators were**

- Dr Karen Blades, Clinical Lead for Dementia
- Dr John Hague, Clinical Lead for Mental Health
- Dr Gill Collighan, Consultant in Later Life at Ipswich Hospital
- Debbie White, Director of Operations at NSFT
- John Lambert, Personalisation and Partnerships Manager, Suffolk County Council
- Dr Mark Lim, Clinical Associate Director of Redesign

### **3.1 DELEGATES' VIEWS ON DIAGNOSIS**

The diagnosis rate of people living with dementia is currently 42% and the aspiration is to increase this to at least 75% by 2015/16. Difficulties at various stages in the journey to diagnosis are outlined below.

#### ***Recognition of Dementia Symptoms in the Community***

A public awareness of the positive points of diagnosis is essential; there may be no cure, but dementia can be sustained. Many families do not understand the early signs of dementia, others are in denial, are reluctant to seek a diagnosis so would benefit from knowing its value. Delegates expressed a wish for a pre-diagnosis element of care, slowly moving into discussions about dementia diagnosis itself. A diagnosis of dementia opens up access to specific services and resources. More information should be available about post diagnosis care and the dementia helpline. Of benefit would be a public information campaign to address the stigma of dementia and encourage people to seek diagnosis. There is a need to address the risks of false positive diagnoses, the losses of diagnosis like one's ability to drive, ability to be taken seriously, the loss of independence.

#### ***Encouraging the GP to diagnose more patients:***

Delegates felt GPs should get over a reluctance to diagnose, especially where cases are very obvious. People with dementia do not always have insight into their problem and self reporting is low yet GPs might not be willing to listen to family members and carers when they seek support for diagnosis. GP responses to concerns of relatives about a loved one's memory should not result in a game of 'wait and see'. Diagnosis delays can run into 18 months, which is unacceptable. Sometimes a diagnosis of dementia is on the patient file but the patient and relatives are unaware and are not informed by the GP. So patients may not know they have been diagnosed with dementia. There can be communication difficulties between GP practices and secondary care, as well as the GP and families about diagnosis, especially information on discharge summaries.

### ***Information at GP Surgeries***

Better information for primary care staff, family and carers can prevent crises. Difficulties have been experienced by the Alzheimer's Society in trying to get leaflets into GP surgeries. Public Patient Involvement groups might help disseminate information and leaflets. It might be of benefit to patients to discuss matters with link nurses who have a mental health background. How do we get information to patients without family or friends?

### ***Equality Matters***

Rurality is a major equality identifier in Suffolk, with those in rural areas most likely to be isolated, with poor transport links, and experiencing difficulty getting appropriate and timely information. There needs to be quicker identification of elderly couples where both partners have dementia but with one partner more severely affected than the other. Diagnostic and care services should be available closer to communities, with a more pro-active approach between health and social care.

People aged over 65 are likely to have difficulties with physical and sensory disabilities - vision, hearing and mobility. Information provided in just written form can be inaccessible to the blind, who may prefer information on compact disc; the hard of hearing may not be able to access telephone help lines and may access information more effectively in different ways. This age group is least likely to use the internet and websites.

Language and cultural barriers can be overcome by working with black and minority ethnic (BME) groups especially those *with the largest ageing populations*, the Asian and Caribbean communities. BME communities present late for services and require investment in interpretation and translation services; and investment in initiatives that overcome cultural and religious barriers.

### ***Secondary Care***

The Commissioning for Quality and Innovation Payment (CQUIN) helps to identify and screen patients with memory problems. Ipswich Hospital Trust and Community Hospitals are commissioned to screen anybody admitted who is over the age of 75 for memory difficulties. However often inadequate information is given to patients before they are discharged back to their GPs. Community Mental Health Teams should be more involved in diagnosis. Clinicians on inpatient wards can be unwilling to make or confirm diagnoses.

Delirium was repeatedly raised as getting in the way of accurate dementia diagnosis. False positive diagnosis can have catastrophic repercussions where patients are put at risk of losing their homes or find themselves in care homes on recovery. Patients should only be assessed for dementia once their delirium had cleared.

### ***Memory Clinic***

The Memory Clinic team at Ipswich Hospital is working to full capacity. There can be administrative problems with inadequate patient information from GPs to the Memory Clinic. Missing details of (for example) next of kin on referral forms can mean unnecessary diagnosis delays. To attend the Memory Clinic, patients have to have a carer in attendance and must travel to the clinic. There are people who just cannot get themselves organised to attend the Memory Clinic; people in very rural areas, those without family or friends and so on.

### ***Nursing and Residential Care Settings***

If 80% of residents in care homes have suspected dementia, then there should be a campaign to diagnose them. GPs should be more involved locally, perhaps offering staff training and medication support. Paid carers in residential care and nursing homes need better training.

### ***Generally***

There are not enough people to diagnose dementia, and nurses and GPs need to be trained to meet some of the need. More nurses should be able to undertake aspects of screening like the assessments and blood tests. Primary and Secondary care services need to be bolder about making diagnoses, even though they are the conveyors of bad news.

## **3.2 DELEGATES' VIEWS OF POST DIAGNOSIS SERVICES**

### **National Frameworks**

We need to plot the national targets, waiting times, referral to treatment and Key Performance Indicators and make sure Suffolk is on target.

### **Knowledge and Understanding**

Family and friends need support to understand 'normal' behaviour and what is not. It would be beneficial to have more dementia advisors allocated to patients to take them throughout their dementia journey. There are currently 7 part time advisors covering 500 patients across the whole of Suffolk. Community groups should be encouraged to support people when they have just been diagnosed. There are village projects in Debenham, Aldeburgh and Shotley that support service users and carers.

It is crucial to differentiate life experience between rural and urban societies. Knowledge base and expectations of services can vary significantly.

### **The Range of Services Available**

Much as they need post diagnosis services, what the different dementia providers do is a mystery to many patients, carers and other dementia services. Some patients would benefit from cognitive rehabilitation in community hospitals. More community services within primary care would reduce the need to travel great distances to access services at one central place. A person in crisis can suddenly be inundated with a bewildering range of dementia services in uncoordinated fashion, and this is overwhelming for patients and carers.

### **Dementia Service Users**

Medical reviews are very important though not always done. Memory Assessments over the phone do not always provide a good representation of the situation on the ground. People with dementia have other diagnoses, e.g. falls, heart disease, and need to be aware of their choices. People who are first seen in secondary care arrive much further down their dementia journey and tend to arrive in crisis. Sometimes people have no relatives or carers. Where both partners in a couple have dementia, with one more affected than the other, services must be local or else it becomes impossible to access any service at all. There is less dementia service provision in nursing and residential care homes. Patients with delirium should be followed up on hospital discharge to assess whether they may have further problems with memory loss.



### **Equality Matters: Sensitivity to Rurality, Culture, Language, Religion etc.**

How does Suffolk create a more 'dementia friendly' system for those who are isolated? A regular mobile Dementia Awareness Bus (similar to the dementia screening mobile unit) with information and support services that stops close to where people live, would be helpful in rural areas and address the transport challenge. Certain organisations avoid home visits because of the transport costs.

There should be attempts to increase cultural awareness and training to support groups from minority ethnic communities. Culture, faith and language are important for people with dementia and many times the staff do not represent the backgrounds of the patients they care for. Specific diets are very important to certain groups, Muslims, Jews, Hindus etc.

### **Carers**

More support for carers means patients remain in the community longer without entering residential or nursing care homes. There is not enough respite in Suffolk and little transparency in how it is provided or can be made available. The diversity of provision needs to include a sitting service. There is currently no co-ordination of respite care services. Funding is running out with the possible withdrawal of the befriending service, which is the main thing that keeps carers sane. Some carers are very private and will not accept help. However carers should be encouraged not just to engage with dementia services at moments of crisis, but to seek support before that. 'Waiting for a crisis' causes many carers to acquire long term health conditions.

### **Information**

A *Directory of Dementia Services* would be of benefit and provide clarity. Information needs to be readily available for all and leaflets are more easily accessible than websites for this client group, many of who have elements of sight and hearing loss. Many organisations do overlapping work, which is confusing. There are far too many signposting services and patients can be swamped with data and phone numbers and leaflets. The Dementia Advisory Service should guide them through all of this. It would be helpful to have one Dementia Number with trained staff at the end of it.

The various IT systems need to be able to speak to each other to enable information sharing between providers. There needs to be a joint Operational Policy across providers – health, community health and social services. Patients fall through the network of care for lack of information sharing between care organisations.

### **Training**

Ipswich and East Suffolk CCG needs an agreed training strategy across care providers. There is inadequate dementia training for hospital staff, primary care, nursing and residential care homes, domiciliary carers and carers who are family and friends. The majority of paid carers who provide standard social care packages are not dementia trained. Unpaid carers need to be skilled up and 15-20 minute sessions are not enough.

### **Co-ordination of services**

The whole workshop raised the necessity for joined up working; a local co-ordinator role in each locality that would provide consistency for dementia patients and their carers. This Co-ordinator role might be a named social worker attached to a specific GP practice. The co-ordinator would know when GP and hospital appointment times were, the statutory and voluntary care services and link with patients and carers. They would have access to service transfer information and make it available as and when necessary. There are currently too many referral forms and a desire for one

place where people know to go and trust with all their queries. The Co-ordinator role needs to be provided in a holistic way.

Examples of how other care groups manage patient information was discussed and the importance of having all a patient's notes in one place. Examples were given of the Blue Book, where all service providers for the same patient make a note of each visit, professional updates and sign the book. This helps carers, the patient and all other service providers understand the different roles. The Alzheimer's Society has a 'This is me' document with lots of pertinent personal and professional information on each patient, which could be rolled out to dementia patients in care homes. The *Yellow Folder* is used by End of Life Workers; there are also Electronic Tags that could hold patient information; the Priory uses health passports.

### **Joint Commissioning of Dementia Services**

There was a general desire for post diagnosis services to be more jointly commissioned, co-ordinated and co-located between health, social care, community health services and the voluntary sector.

Joint commissioning of dementia services needs to be expanded and improved. It is unsustainable for long term dementia services to be commissioned from small pots of short term funding. The dementia intensive support team only works from 9am to 6pm and not weekends, which is a major gap in provision. There should be step up and step down beds for patients with delirium to enable a proper dementia assessment after the delirium has passed. Very few care homes can afford to keep dedicated respite care beds. Rapid Assessment Interface and Discharge service (RAID) needs to drive up capacity and quality in the community. Assistive Technology is under used in Suffolk but could help keep track of patients who might wander off. Many of these services have an impact on health and social care and should be jointly planned and commissioned.

## **3.3 DELEGATES' VIEWS OF WHAT SUCCESS WOULD LOOK LIKE**

### **Public Health Campaign**

A campaign of public awareness raising would improve diagnosis of the other 58% of the population with undiagnosed dementia. Advertising campaigns improving recognition of symptoms, presenting diagnosis in a positive light, providing information about post diagnosis services would help. The campaign should address the bad news head on, like false expectations regarding medication, the fact not all dementia receives major recovery. Living well with dementia needs to be the message that goes out. Dementia is everybody's business. The younger generation in schools and colleges should be reached to begin conversations about social issues.

### **Diagnosis**

Success would be achieving 100% diagnosis of everybody who has dementia. Everybody should know where to go for early diagnosis, within 2 – 3 weeks of symptoms being recognised. There should be a common screening tool. More professionals need training in diagnosing dementia, especially in primary care. Late diagnosis amongst people who live in rural areas and BME communities should be addressed. CQUIN assessment for memory problems should be available in primary care and not just on inpatient wards. Success would be delirium no longer confusing dementia diagnosis, with people referred for assessment and diagnosis after their delirium has cleared.

### **Post Diagnosis**

Success would result in fewer crises in the community and in hospitals. Services would be embedded locally within communities with good communications with hospitals, GPs etc. There would be improved access for people in rural areas and those from minority ethnic groups.

### **Information**

A Dementia Directory and one Dementia Telephone number for public and service users would be ideal. There should be less signposting services and more actual services. Information in leaflets should be in easy language to understand and in different ethnic languages as required. Information should be designed knowing that many older people are deaf or hard of hearing, blind or with visual impairment.

### **Service Co-ordination**

There should be local accountability, a single GP practice with named worker responsible for all local cases in the locality. Currently access to a social worker depends upon the Fair Access to Care criteria however success would mean dementia patients are allocated a social worker or other permanent co-ordinator. Service users would never be discharged from local services since dementia is incurable.

There needs to be organisational change, professional co-operation between providers with jointly agreed procedures. Securing patient consent to share information across providers would require such co-operation. There should be jointly developed care pathways. Service integration should be possible at local level between community health services, dementia intensive support team and other services.

Patient information needs to be held in a central place with easy access by a named professional. IT systems would speak with each other as it would improve information sharing across service providers, cut down on the large number of unnecessary cross referrals and processes.

Such co-ordination would mean more patients would stay at home for longer.

### **Service Co-Location**

People with dementia will tend to be over the age of 65 and likely to have problems with frailty, mobility, sight and hearing so co-located dementia hubs with access to a range of professionals would suit them best. Models could include regular virtual meetings across different providers – social services, primary care, end of life care etc. The current geographic boundaries of the agencies are confusing with some locations considered to be Ipswich and East Suffolk CCG, but fall within what Suffolk County Council refers to as South. Suffolk Community Healthcare has different boundaries that cut across the CCG and the Suffolk County Council boundaries. At the proposed dementia clusters, a patient should be able to access services including voluntary sector, primary care, secondary care and social services. Such dementia services would be compliant with NICE guidance and still be led by a Consultant in Older People's mental health.

### **The Services**

A successful service would develop and promote dementia champions, to work with communities and develop dementia friendly environments and communities. Success would see more dementia advisors and cognitive rehabilitation for patients in the community. Some services could be provided by a mobile unit, like a

Dementia Bus, or Coffee caravan moving from one location to another. Success is the availability of good quality respite care with co-ordination and support from social care professionals. Assistive technology – just checking devices, mind me - are all currently underused in Suffolk and more patients should have access to them.

### **Residential and Nursing Care Homes**

Success would mean knowledge of exactly what care homes offer dementia patients, and what staff training is provided. Every resident with dementia would be diagnosed. People from minority communities would be less reluctant for their family members to go into care homes. There should be activity co-ordinators in care homes that provide sessions rather than respite care beds.

### **Training**

Success would be joint training across sectors. More skills training in care homes, primary care, carers. A 12 week dementia medication course is available. More support workers in community mental health teams need to be trained up.

### **Joint Commissioning**

Success would be joint commissioning dementia services, with pooled budgets between health and social care. This would reduce the commissioning of similar or competing services. Learning from the many pilots that have gone before would inform commissioning intentions. The voluntary sector would spend less valuable time in fundraising and more providing care. They would have long term contracts for core funding to allow continuity and sustainability of projects. The enhanced care budget is currently under spent, which is a tragedy. Commercial factors should not prevent integration and unnecessary competition between organisations should be avoided. Successful joint commissioning would mean provider agencies would play to their strengths and work in partnership. There are models from abroad that IESS could learn from in Swedish and Netherlands.

## **3.4 CONCLUSION**

The feedback received from delegates at the Workshop will be used by Ipswich and East Suffolk CCG and Suffolk Adult and Community Services to inform their commissioning intentions to redesign dementia services. In particular agreement needs to be reached between the 2 organisations as to the extent and nature of joint commissioning arrangements. These arrangements are needed to underpin the required redesign and development of new dementia services in accordance with the aspirations of those affected by dementia and by delegates at the workshop.

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## DEMENTIA WORKSHOP

1.30 – 4.30pm, Tuesday 26 February 2013, Bucklesham Suite, Trinity Park  
Conference Centre, Felixstowe Road, Ipswich, Suffolk IP3 8UH

### A G E N D A

1.30pm	<b>Sandwich Lunch</b>
2.00pm	<b>Introductions</b> , <i>Dr Karen Blades, IES CCG Dementia Lead</i> <ul style="list-style-type: none"> <li>❖ Aims of the Workshop</li> <li>❖ The Facilitators</li> <li>❖</li> </ul>
2.10pm	<b>Dementia in Ipswich and East Suffolk</b> , <i>Dr Mark Lim, Chief Redesign Office, IES CCG</i>
2.20pm	<b>Current Provision for People Living with Dementia and their Carers –</b> <i>John Lambert, Personalisation &amp; Partnerships Development Manager Adult &amp; Community Services, Suffolk County Council</i>
<b>TABLE WORKSHOPS</b>	
2.30pm	<b>Diagnosis</b> What are the current problems with dementia diagnosis? How can diagnosis be improved?
2.50pm	<b>Post Diagnosis</b> What are the challenges, gaps and pressure points with current provision? How could the gaps you have identified be improved?
3.10pm	<b>Developing Cohesive Services across providers</b> What are the challenges to having more cohesive services? How could this be improved?
<b>TEA COFFEE BREAK</b>	
3.50	<b>What would success look like?</b>
4.00	<b>Plenary Session – Chaired by Dr Karen Blades</b> The main issues with dementia service provision in IES CCG

**APPENDIX II**

**ATTENDANCE LIST**

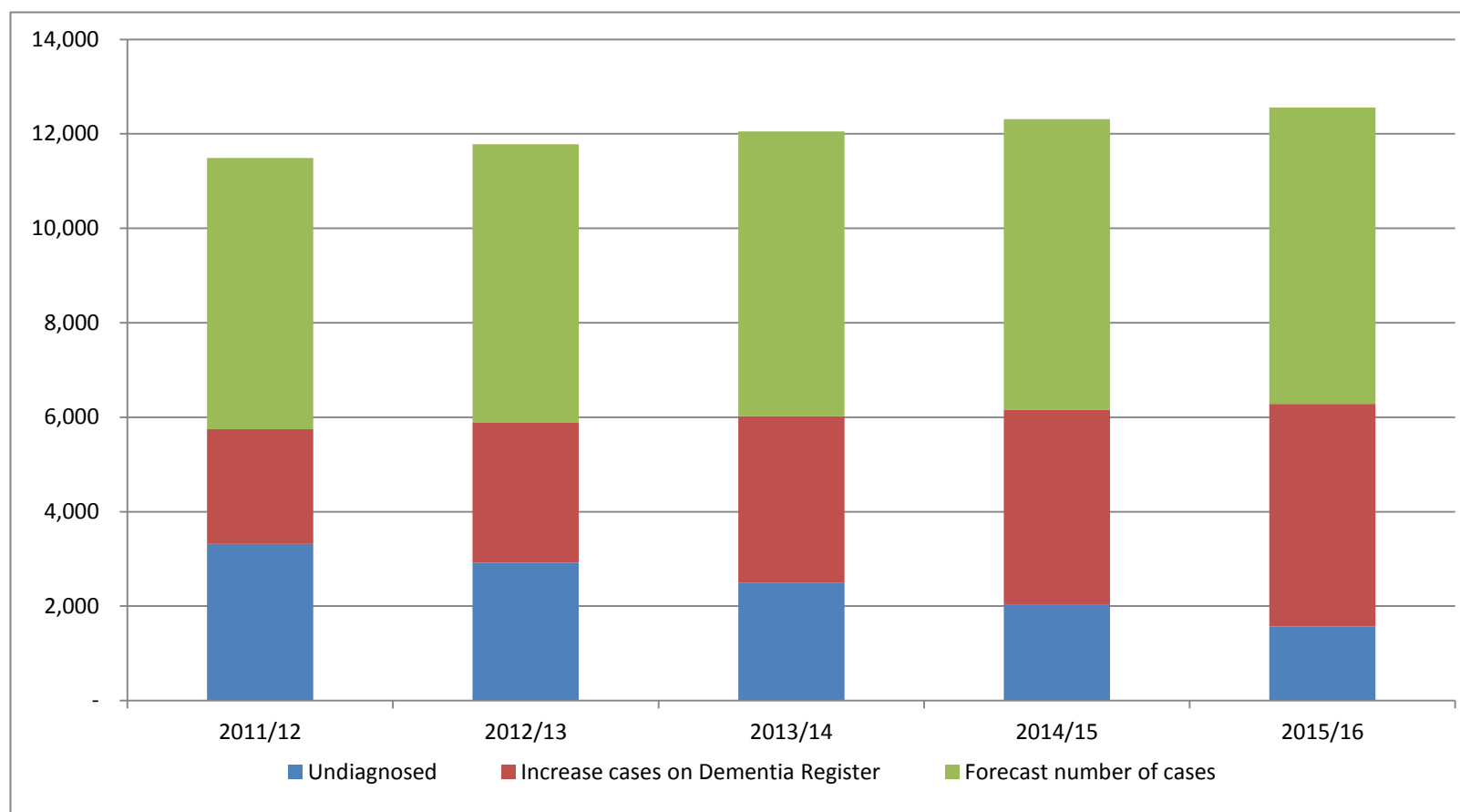
**Dementia Consultation Workshop Attendance List Tuesday 26 February 2013**

Contact Name	Nursing Home/Organisation
Pearly Gupta	NHS Suffolk (Public Health)
Alan Bramwell	Ipswich and East Suffolk CCG
Anna King	NSFT
Anna Macaulay	Care UK
Ashok Bhatt	Independent BME
Cheryl Milldown	Baylham Care Centre Private
Chris Rowland	Ipswich and East Suffolk CCG
Clare Smith	Development Manager
Councillor Albert Grant	Caribbean Club
Debbie White	Director of Operations NSFT
Dorothy Mukasa	Ipswich and East Suffolk CCG
Elena Jamieson	Consultant - IHT
Fiona Knott	Suffolk Family Carers
Fiona Raffe	Cluster Manager - Dementia
Fran Pugh	Leiston Old Abbey
Gail Collyer	NSFT
Gillian Colligan	Mental Health liaison
Kerry Overton	Health Watch Suffolk
Heather McRoberts	Allied Health Care
Helen Fairweather	Headway
Helen Whight	NSFT
Jane Benten	(SERCO) Suffolk Community Health Care
Janet Beacham	Alice Grange, Kesgrave
Jo Marshall	Sue Ryder - The Chantry
John Hague	Ipswich and East Suffolk CCG
John Lambert	Development Manager
Julie Sadler	Dementia Lead - IHT
Karen Blades	Ipswich and East Suffolk CCG
<i>Katie Jacobs</i>	<i>Ipswich and East Suffolk CCG</i>

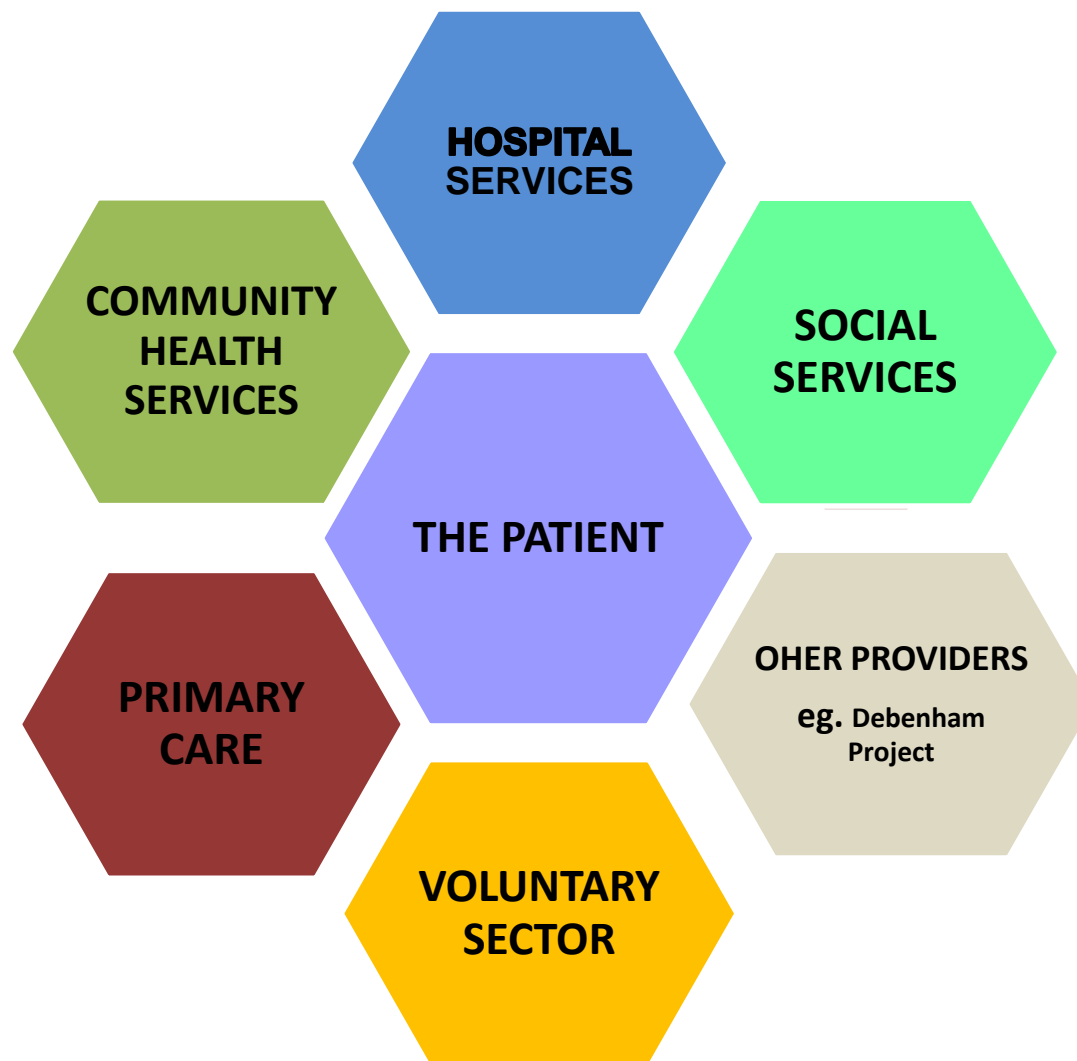
Contact Name	Nursing Home/Organisation
Melanie Norris	Care UK
Marianne Smith	Allied Healthcare
Sharon Cozens	Age UK Suffolk
Naomi Nunn	Norwood House
Patrick Anderson	Suffolk County Council
Phanuel Mutumburi	Ipswich and Suffolk Council for Racial Equality
Prema Dorai	Baylham Care Centre Private
Rachel Fitton	The Partnership in Care
Richard Ball	The Priory Grange St Neots
Rob Butler	Consultant
Veronica Akkoffi	Caribbean-African Community Health Support Forum
Steve Tucker	Later Life lead
Sue Nicholson	Alzheimer's Society, Suffolk
Sue Vincent	Alzheimer's Society, Suffolk
Sandra Bailey	Dementia Intensive Support Team
Tina Larter	Ipswich and East Suffolk CCG
Willie Cruickshank	Norfolk and Suffolk Dementia Alliance
Shayra Begum	Bangladeshi Support Centre
Abby Whiting	Monmouth Court Nursing Home
Lorraine Parr	Ipswich and East Suffolk CCG
Louise Burrows	Suffolk Age UK
Lynden Jackson	The Debenham Project
Maddie Baker-Woods	Ipswich and East Suffolk CCG
Marianne Smith	Allied Health Care
Mark Lim	Ipswich and East Suffolk CCG
Mark Reed	Cluster Manager - Dementia

**DEMENTIA PREVALENCE CALCULATOR – AMBITION TO INCREASE DIAGNOSIS FROM 42% TO 75%**

	2011/12	2012/13	2013/14	2014/15	2015/16
<b>Undiagnosed</b>	<b>3,317</b>	<b>2,918</b>	<b>2,493</b>	<b>2,043</b>	<b>1,570</b>
<b>Increase cases on Dementia Register</b>	<b>2,429</b>	<b>2,974</b>	<b>3,532</b>	<b>4,112</b>	<b>4,710</b>
<b>Forecast number of cases</b>	<b>5,746</b>	<b>5,890</b>	<b>6,028</b>	<b>6,155</b>	<b>6,280</b>
<b>Diagnosis rate</b>	<b>42.0%</b>	<b>50.5%</b>	<b>58.6%</b>	<b>66.8%</b>	<b>75.0%</b>

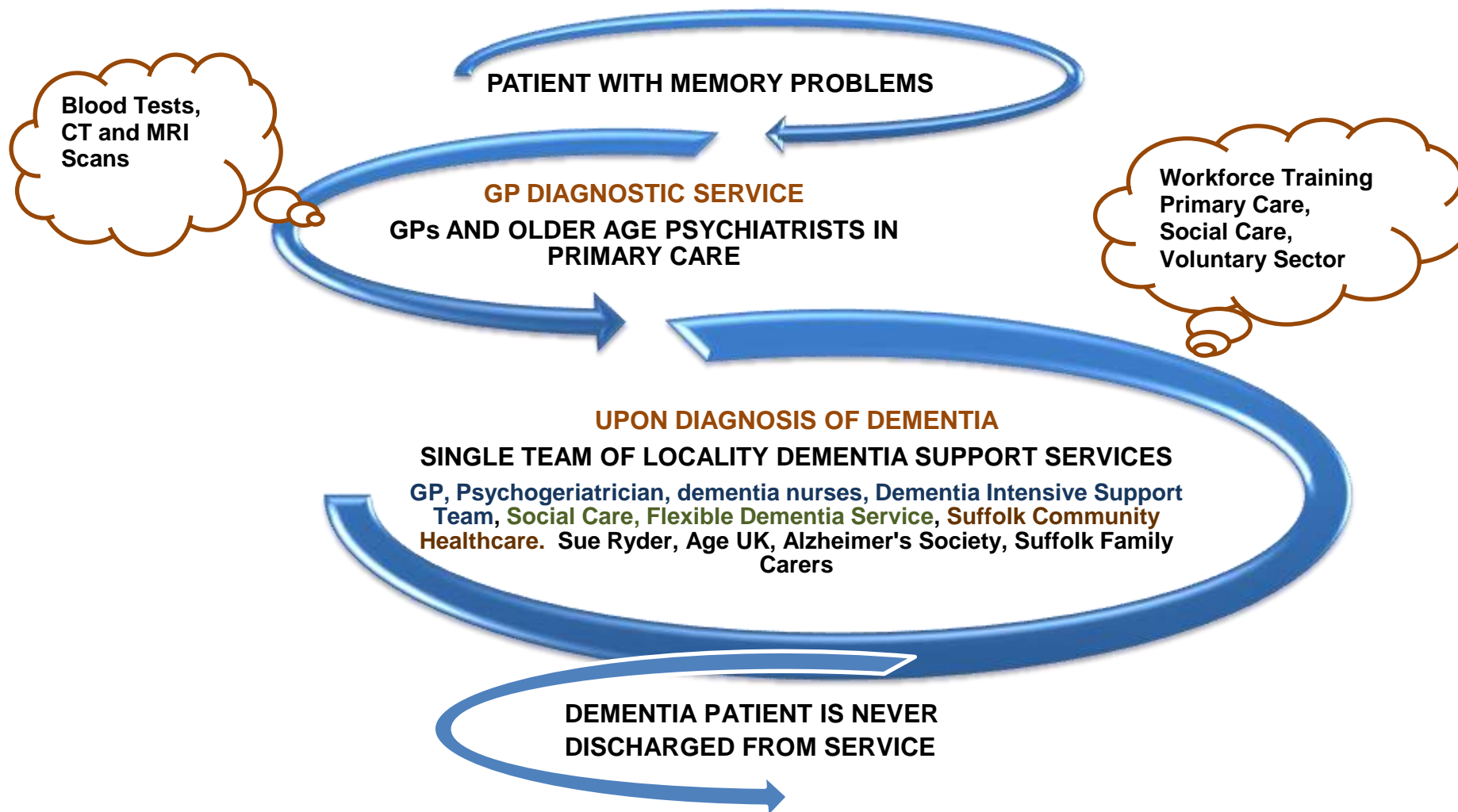


## CURRENT DEMENTIA SERVICES





## VISION FOR REDESIGNED DEMENTIA SERVICE





Ipswich and East Suffolk  
Clinical Commissioning Group

Rushbrook House  
Paper Mill Lane  
Bramford  
Suffolk  
IP8 4DE  
Tel: 01473 770056  
15 February 2013

Dear Colleagues,

Dementia Services within Primary Care

As many of you are aware, and have already contacted me with concerns, we are facing a demographic time bomb with respect to increasing our capacity to diagnose dementia and then supporting dementia sufferers and their families/carers to live with the disease.

In fact modelling has predicted we need to increase our capacity by up to 50 % in the next 3 years alone. This is based on a diagnostic pick up rate of 75% compared to our current 42%. At the CCG we are working with our NSFT clinical colleagues to produce a sustainable dementia service, of which more details at the next Educational meeting at Trinity Park on 27<sup>th</sup> February.

At this stage we would like to sound out practices to establish if there is an appetite for increasing dementia diagnosis in primary care. We would be after at least 10 practices to offer a diagnostic service, with full education and support from a community based psychogeriatrician. This may well involve an IT investment by the CCG and extra funding to ensure your practice is a *Dementia Friendly Environment*.

The time commitment would likely be half to one day a month (depending on uptake), would be based in your practice, and would be remunerated adequately.

At this stage I am only after an expression of interest by practices.

Do please discuss amongst your practice colleagues. We hope this service will be sustainable, local and high quality, based on established successful models around the country. It has the full support from our consultant colleagues in the Memory Clinic.

Many thanks for your time - please reply to me directly at [karen.blades@nhs.net](mailto:karen.blades@nhs.net). Hopefully see you on the 'Dementia' table at the GP Education Event on 27<sup>th</sup> February.

Yours sincerely,

Dr Karen Blades FRCGP  
Ipswich and East Suffolk CCG Dementia Lead  
[karen.blades@nhs.net](mailto:karen.blades@nhs.net)

## **GP EDUCATION EVENT – DEMENTIA TABLE**

### **WEDNESDAY 27 FEBRUARY 2013**

Dr Karen Blades and Dorothy Mukasa

- 1. Issues Raised by GPs Regarding Diagnosis in Primary Care**
  - What is the point of diagnosis? Prevention? Treatment?
  - What is the capacity of the diagnostic services to manage this increase?
  - Is there more money to GPs for doing this?
  - Gaming of the System – disincentivised to code patients.
  - The scans are still done at the hospital, this has to come with funding
  - People who are housebound also need to be diagnosed
  - What is the best screen tool?
  - What is the point of scoring patients, and these screening tools?
  - In order to secure points on the NHS Quality Outcomes Framework (QOF), a GP can take substantial time recording detailed dementia diagnosis data and then by mistake miss recording one test result. This small error results in them not getting any QOF points for the patient.
  - To secure QOF ratings, GPs get points for blood test results and scans which need to be recorded on the computer. Registering of patients in nursing homes would increase the diagnosis rates quite significantly.
  - Recording of Blood Tests – discharge summaries are automatically sent them
  - CQUIN blood test results should be sent to GPs for their files as a matter of process.
  - GPs need help with geriatric patients around psychosis, mood disorders
  
- 2. Post Diagnosis Concerns**
  - GPs would like a leaflet, or other resource, with phone numbers of all dementia service providers.
  - There is a danger of over diagnosis, there will be dementia stigma associated with diagnosis, what about false diagnosis?
  - Are there resources available to provide support after diagnosis? Services are already overwhelmed by dementia patients, there are no services.
  - Diagnosis helps social services secure greater resources for patients.
  - Regarding Shared Care Agreements – since Aricept is now off patent and can be prescribed by GPs, there is less need for dementia shared care agreements.
  - Post diagnosis resources are required to develop services and have something to offer patients.
  
- 3. Other**
  - 2% of dementia patients are below the age of 65, how are we targeting them?
  - Is there new funding for this project? Budgets for psychogeriatricians are being cut, the prescribing budget is being cut, the voluntary sector budget is being cut.
  - With regard to prescribing, Aricept is now off label so is cheap.

## EVALUATION OF DEMENTIA SESSION

Dementia – Dr Karen Blades and Dorothy Mukasa					
How useful did you find the presentation? 1 = not very useful, 5 = very useful					
1	2	3	4	5	
0/59	0/59	10/59	23/59	23/59	<i>No response 3/59</i>

### **Any comments**

- “A great deal of effort to be made in diagnosing a condition which is not curable and which many patients do not want cooperation with.”
- “An integrated service with GP diagnosis of dementia is a must”
- “Clear rationale given, sounds like a great opportunity”
- “Didn't handle questions well - why we need to diagnose dementia in residential and nursing homes”
- “Excellent”
- “Excellent idea”
- “Excellent idea re: service provision”
- “Good explanation of new service”
- “Good sales pitch for dementia moving into primary care. Convincing speaker”
- “Good service for increased diagnosis of dementia”
- “Great idea enthusiastically presented - feel inspired”
- “Great ideas put forward”
- “Interesting concept if it can be delivered”
- “Interesting to hear what is happening”
- “Is there any benefit to diagnosing very elderly patients who are already in residential care?”
- “Karen is an optimist! Need better provision of services in the community”
- “Not many answers available if referrals were to increase”
- “Raises big issues re: ability to cope and vastly increased numbers of dementia patients and adds work in general practice”
- “Sounds like a good idea, make sure it is properly funded”
- “Sounds like a great service and needed, would like to get involved. Worried about funding and capacity of services post diagnosis”
- “Very helpful - past experience with memory clinic was very poor – 18 months from seeing GP to diagnosis is not efficient and this is needed”

## JOINT COMMISSIONING

### 1. INTRODUCTION

The Department of Health looks to joint commissioning as a way to secure integrated services between Health and Social Care. The authorisation process looks favourably on strategic planning and joint procurement of services by Health and Social Services. NHS England (formerly the NHS Commissioning Board) has a framework for collaborative commissioning between clinical commissioning groups. The current Health and Wellbeing Strategy is across 3 Clinical Commissioning Boards and Suffolk County Council. Some service areas by their very nature lend themselves to joint commissioning, such as mental health and learning disabilities, but it does require planning structures to support the process. The *Joining Up of Services for Older People* review carried out for NHS Suffolk and Suffolk County Council in 2012 recommends dementia services as an area for joint commissioning.

### 2. OPTIONS FOR JOINT WORK WITH SOCIAL SERVICES

a. *Joint broad strategy between CCG and SCC to support common area of care*

The two agencies agree an area of work and levels of funding, but then each agency develops their own specification and delivery plan. There would not necessarily be joint performance management of the work.

b. *The CCG and SCC enter into a formal Section 75 agreement*

The framework provided by the National Health Service Act 2006 means money can be pooled between health bodies and health-related local authority services, functions can be delegated and resources and management structures can be integrated. The Section 75 arrangements are designed to ensure that 'partnerships' are properly constructed and supported within the legislation with:

- One Lead Commissioning agency
- A pooled budget
- An integrated service

#### 2.2 Services That Would Benefit from Joint Commissioning

- Multi disciplinary integrated dementia teams
- Voluntary sector service provision
- Training

### 3. Formalisation of Arrangements

Audit and review over the last few years have consistently emphasised the importance of partnerships being properly governed and accountable, and the formality of arrangements. This is particularly so in arrangements where it is intended that one agency might manage another's staff or service functions as a part of joining up service provision, or where one agency is acting for another in arranging care, especially through externally contracted suppliers.

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