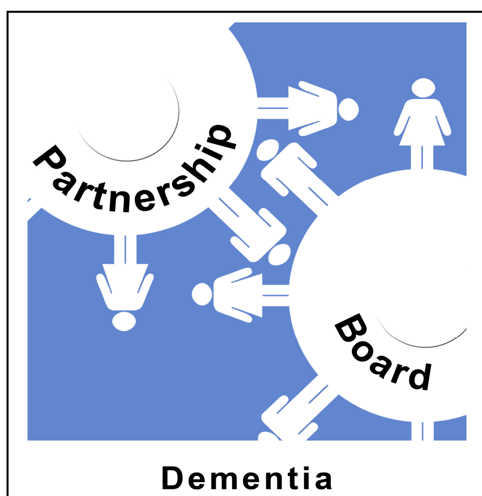


Dementia Partnership Board

AGENDA

Date: **Friday 12 December 2014**

Time: **10.00 am**

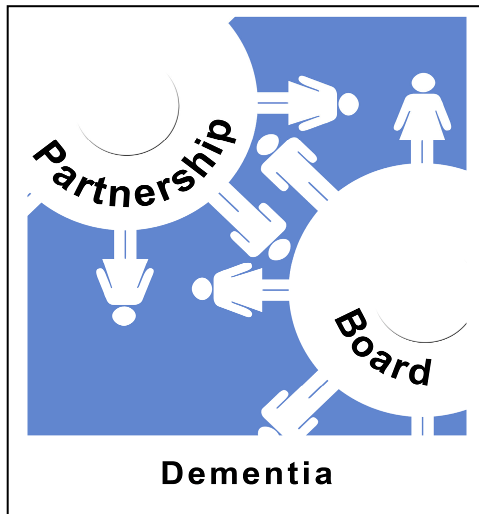
Venue: **Mezzanine Room 2, County Hall, Aylesbury**

No	Item	Timing	Page
1	**Welcome and apologies**	10am	
2	**Previous Minutes** Maxine Foster, Joint Commissioning Manager, Buckinghamshire County Council and Clinical Commissioning Groups		3 - 12
3	**The Care Act** Maxine Foster, Joint Commissioning Manager, Buckinghamshire County Council and Clinical Commissioning Groups	10:10am-10:25am	
4	**Group Session 1: What are the priorities?**	10:25am-10:55am	
Break 10:55am - 11:05am			
5	**Group Session 2: Prioritising the priorities**	11:05am-11:20am	
6	**Feedback / Agreeing the final list of priorities**	11:20am-11:40am	

7	**Buckinghamshire Healthcare NHS Trust - Dementia Work** Noel Scanlon, Interim Deputy Chief Nurse, Buckinghamshire Healthcare NHS Trust	**11:40am-11:55am**	
8	**AOB / Date of next meeting** 13 February 2015, 10am, Mezzanine Room 1, County Hall, Aylesbury	**11:55am-12pm**	

If you would like to attend a meeting, but need extra help to do so, for example because of a disability, please contact us as early as possible, so that we can try to put the right support in place.

For further information please contact: Helen Wailling on 01296 383614
Fax No , email: hwailling@buckscc.gov.uk



Dementia Partnership Board

Minutes
Thursday 25 September 2014

Members in attendance:	
Rachel Daly	Quality in Care Team Lead
Paul Day	Service User / Carer Representative
Maxine Foster	Joint Commissioning Manager
Seema Gadhia	Prescribing Support Pharmacist, Aylesbury Vale CCG and Chiltern CCG
Bernice Henderson	Service User / Carer Representative
Giulia Johnson	Age UK Bucks
Lynne Maddocks	Aylesbury Vale District Council
Dr Brian Murray	Oxford Health
Christine Nash	Age UK Bucks
Nicole Palmer	Alzheimer's Society
Derys Pragnell	Public Health
Pam Taylor	Service User / Carer Representative
Ann Whiteley	Carers Bucks
Christine Whiting	Service User / Carer Representative
Gemma Workman	Bucks County Council
Others in attendance:	
Beverley Frost	Communications Officer, Adults and Family Wellbeing
Debi Game	Bucks Service User and Carer Organisation (SUCO)
Helen Wailling	Democratic Services Officer

No	Item
1	**Welcome / Introductions** Maxine Foster introduced herself, and said she would be chairing the meeting. Each member introduced themselves. Each member had been given a piece of coloured card, which they were asked to raise in the air if anyone said something which they did not understand, i.e. jargon, speaking too quickly etc.
2	**Background** Maxine Foster said that she had recently taken over as the Lead Officer for Dementia at Buckinghamshire County Council. There had never been a Dementia Partnership Board before and it was very important that they had one. There were a lot of challenges ahead and a lot of work to do. The Joint Commissioning Strategy for Dementia ran out in 2014, and they would need to think about that. The Board also needed to ensure that the voice of the whole community that provided support for dementia patients was heard. They also needed to look at the priorities for the Voluntary and Community Sector that did such vital work in supporting dementia. They needed to look at where there were gaps in services.
3	**Terms of Reference** The Terms of Reference had been circulated. They set the scene and the priorities, and the 'rules of engagement' for the Board. The Terms of Reference also provided a mechanism to resolve issues. Maxine Foster suggested that the Terms of Reference be discussed at the next meeting. The Terms of Reference were generic, but they needed to ensure that they were correct for the Dementia Partnership Board. The Terms of Reference also included the membership list for the Board. There would be some people who would receive Minutes but would not always attend meetings. It was critical that they decided if they had the right representation and that they addressed any gaps. Wycombe District Council had asked if Lynne Maddocks could represent all four District Councils on the Board. Lynne Maddocks said that it was more about whether it was relevant for District Councils to attend the Board meetings at all. **Action: LM to consider if it's more appropriate to attend Memory Friendly Community working group.**

	Rachel Daly asked if there would be representation from Buckinghamshire Healthcare NHS Trust (BHT) or other providers. **Action: HW to re-contact BHT, Care Management and MKB Care.** Seema Gadhia asked about representation from the CCGs. Maxine Foster said that Dr Stephen Murphy and Dr Alison Banks had been invited but had sent apologies. Dr Alison Banks could only attend Friday meetings, so future Board meetings would be on a Friday. Debi Game noted that on the other partnership boards, they aimed for 50% of the Board to be service user / carer representatives. Bernice Henderson said that the Board seemed at too high a level, and that the main issue for carers was to find somewhere for people with dementia to go during the day. Maxine Foster said that they were looking at creating a service user and carer network, which would look at the gaps and needs. It was absolutely critical to have service and carer engagement on the Board. **Action: BH to consider with DG joining the User and Carer Network** Members also suggested that Bucks Care, Safeguarding Services, Bucks MIND, Healthwatch Bucks and Jo White should be added to the distribution list – **Action: HW**
4	**Memory Assessment Closer to Home** Dr Brian Murray told members the following: • The Prime Minister had announced a project two years previously to put money into dementia care and diagnosis. This funding was a one-off and was not ongoing. • Oxford Health NHS Foundation Trust (OHT) had met with the Clinical Commissioning Groups (CCGs) and Age UK to further develop the Memory Clinics, which were already held in Aylesbury, Amersham and High Wycombe. • They had put Memory Clinics into GP surgeries around Buckinghamshire, and these were held once a week in Buckingham, Haddenham and Stokenchurch. There was also a Memory Clinic which alternated between Burnham and Denham. There were now seven Memory Clinics held in Buckinghamshire every week. • They had also wanted to change the way in which the Clinics worked, and to compress the process. For instance, having patients go for a scan before they had an appointment with anyone from OHT. After the scan they would attend the Memory Clinic and see a doctor and a nurse at the same time. The only wait was for the scan (six week wait). This was a much more efficient care pathway. • After a patient had attended the Memory Clinic, they would be given their diagnosis, with a companion present if they wished. A prescription for memory-enhancing drugs could be made at that time. • All the Memory Clinics had a contact telephone number. • They had linked this work to Age UK and the Alzheimer's Society, who could provide after-support. • The patient would also have a follow-up appointment at the Memory Clinic after three months, and could be referred back to their GP if necessary. • Some patients felt that the new process was a bit rushed, but patients could

always be brought back to the Memory Clinic if necessary.
- Regarding the success rate, it was difficult to separate out the data from the Memory Clinics from the main clinics.
- They were able to report the percentage of people who were seen within eight weeks of being referred by their GP. The figure had been 63% in early 2013, with an average waiting time of eight weeks. The figure for the last three months was 90-93%.
- Where Buckinghamshire had been lagging behind regarding national diagnosis dates, they were now catching up.
- They wanted to sustain the Memory Clinics if they could, and they were absorbing the workload of diagnosing dementia.

Members then asked questions, which are summarised below with the answers.

When did the Memory Clinics start?
They started in October 2013 in Buckingham and were then rolled out across Buckinghamshire.

What benefits are there for someone who obtains a diagnosis of dementia?
Anecdotally we have heard that people with a diagnosis are able to think about forward planning, and make financial arrangements. The majority of people in the early stages of dementia want to be informed. The drugs available are not ‘wonder drugs’ but they do have more benefits than was originally thought.

Is it only patients at the GP surgeries involved who can be referred to the Memory Clinics?
Anyone can be referred to the Memory Clinics, and we have notified all the GP locality groups that the Clinics are available. Patients have to be referred by a GP.

5 Memory Friendly Communities

Gemma Workman gave a presentation (slides attached) and said the following;
- Memory-friendly Communities were a new initiative in Buckinghamshire.
- The aim was to support communities across the County to take positive steps towards supporting people.
- Memory-friendly communities had a high-level of public awareness, were more supportive and ensured access to services and facilities for all.
- Memory-friendly communities were part of the Prime Minister’s ‘challenge on dementia,’ and there would be at least 20 in place across the UK by 2015.
- A survey by the Alzheimer’s Society had found that less than half of those questioned felt a part of their community.
- 1 in 3 people over the age of 65 would develop dementia. There were 6588 people over the age of 65 in Buckinghamshire with a diagnosis of dementia, and this was set to rise to 8123 by 2020.
- It was very important that they supported and empowered people in the community.
- There had been a successful bid from Buckinghamshire in 2012 to the Prime Minister’s challenge fund. A business case was being developed for memory-friendly communities, including a Development Strategy.
- One of the key actions was to engage with stakeholders, such as Chiltern Railways, Lloyds Group, emergency services.
- They were also promoting basic awareness training for customer-focused staff. They were encouraging simple yet effective changes within

	organisations. • A Service User and Carer Network would be set up to inform and give direction to the project. The Forum would meet every six weeks and would feed back into the Dementia Partnership Board. • The next step was for three villages / towns to be selected to be pilot memory-friendly communities. • A recognition scheme was being recommended which would provide set criteria, and would promote the development of action plans. It would also enable monitoring and recognition of good work. Paul Day asked if they had the figures for people with dementia under 65. Nicole Palmer said that the Alzheimer's Society Report re: dementia in people under 65 had just been published and would be circulated to Board members **– NP/HW** Christine Whiting asked about the population of Buckinghamshire. Dr Brian Murray said that it was about 480 000 (not including Milton Keynes). Giulia Johnson asked if there had been any outcomes from the case studies. Gemma Workman said that many areas were now in the evaluation process. Dr Brian Murray said that some benefits were hard to measure. He gave the example of a memory-friendly community in Crawley, in which a bus driver got out of the bus to get a passenger with dementia who he knew had got off at the wrong stop. Rachel Daly referred to vascular dementia and said that it was not always the memory which was affected. Gemma Workman said that the training would include other issues, such as mobility and speech. Rachel Daly referred to people in the later stages of dementia without a diagnosis, and asked how they could engage with them. Gemma Workman said that there was inter-generational work and that in some areas young people had gone into care homes to spend time with the residents. Rachel Daly said that this happened once a year in Buckinghamshire but that it needed to be more often. Ann Whiteley said that a memory-friendly community would be a challenge, and referred to some work carried out by Stirling University. Paul Day noted that GPs tended to be bad at diagnosing early onset dementia. Dr Brian Murray said that the symptoms tended to be quite subtle with atypical features.
Break	
6	**Recognition Process for Dementia Friendly Communities** Karishma Chandaria, Dementia Friendly Communities Programme Manager from Alzheimer's Society National Office, spoke to members via telephone. The Recognition Process for Dementia-friendly Communities was designed to enable communities to be publicly-recognised for their work. If a community wanted to apply for the Process, there were seven criteria:

	• Local leader to take responsibility locally • Right local structure to maintain a sustainable dementia-friendly community – often a local dementia action alliance was recommended. Organisations needed to meet regularly and to create an action plan. • Raising awareness in key organisations and businesses in the community – enable a platform for networking. Dementia friends had been a massive boost for this, as it was free and it did not need to be delivered by the Alzheimer's Society. The Alzheimer's Society could provide more in-depth training too. • Developing a voice for people with dementia – it was vital to consult people with dementia. There was a need to be proactive (to actively hear people's voices). The Alzheimer's Society was very well-placed to support that. • Raising profile of work to increase awareness, e.g. among ethnic minorities, LGBT communities, people with sight loss. Looking at communication channels e.g. via mosque or temple. • Ensuring focus plans on key areas – the main priorities in a community (e.g. transport in a rural community). Trying to target everyone in one hit is very challenging – better to do it in a phased way. • Reporting on progress – how you will find out if it is making a difference. A brief report is requested at six months and then a self-assessment process after a year. Members then discussed this, and the following points were made: • There was a risk in dementia patients carrying their name and address with them as they could fall into the wrong hands. The Alzheimer's Society had cards which people could use. This linked to consent and supporting people – a balance between risk and empowerment. • There were more people out there who were willing to use details for the right purposes, and the willingness of the community to engage was always impressive. • There had been three burglary cases in Milton Keynes in which people with dementia had been deliberately targeted. • Re: doorstep crime, Trading Standards had an arrangement that banks would report if a vulnerable person took out more than a certain amount of cash. • Age UK had a letter with Trading Standards for people targeted by charities for money. Maxine Foster said that the Board needed to consider whether they wanted to use a national recognition process or a more localised process. Bev Frost asked if there was an evaluation of the Safe Places Scheme. Gemma Workman said that they were struggling to know how to evaluate, as there were no criteria in place. Maxine Foster noted that another potential gap in membership of the Board was community crime watch organisations. **Action: HW to invite a representative**
7	**Safe Places** A paper was circulated (attached). Members said the following:

	• It was about understanding what worked. If they introduced an additional scheme, that could be confusing. • Safe Places was open to joining up, and covered children and any vulnerable person. • There had been discussions on this at Autism Partnership Board and at Mental Health Partnership Board. They needed to ensure that any scheme worked well for everyone. • Safe Places was in other counties too, and people could come into Buckinghamshire from other areas and recognise the same scheme. • A focus group had looked at the Safe Places Scheme and had liked the colours used. • Companies displaying a sticker were being asked to record when someone came in for a safe place. Some companies had a high turnover of staff, so would need to train new staff in how to record this. Maxine Foster said that there needed to be a piece of work around enabling businesses to understand how the scheme could generate increased income. Bev Frost referred to the 'Inform' magazine. The first edition had included information on the Safe Place Scheme and there had been a huge amount of feedback, as people became aware of the Scheme. Debi Game suggested that community police be involved, as they had a wider remit than just crime, and could get buy-in from shop owners. **ACTION: Board to agree the way forward with a recognition scheme at next meeting**
8	**Telecare & a Seek and Find Service** Oliver Stykuc-Dean gave a presentation (slides attached) and said the following: • Assistive Technology describes electronic devices which can enable people to live independently. • The devices are designed to enable and to work alongside traditional care services. • A service called 'seek and find' works via a GPS device, and provides someone's location to around five metres. It can pinpoint individuals, so that they can be found and treated for injuries or taken to a place of safety. 'Seek and find' is used for people who are at high risk of becoming lost or disorientated, or of entering a hazardous area (e.g. a bus station). • Use of Police as an emergency response for this service is a huge use of time. Potentially we can use volunteer networks, third sector agencies and care networks. • Co-ordination of seekers is required, as well as a gatekeeper for the service. All systems need to integrate seamlessly as a network. • Use of GPS is very common as all phones now contain a chip. There should not be stigma attached. It is a piece of consumer electronics used as a choice, to allow freedom. • The 'Buddi' is the size of a key ring, with a battery. Every thirty seconds it sends out a bleep, and provides a six-digit code of the person's location, anywhere on the planet. • There is also an arm band which is a fall detector which sends a text message to the carer if the person falls. • There is a 'sports watch' style GPS which sends out a person's location if they press a big button.

	• There is also a very basic GPS, which looks like a key ring, to reduce stigma. • The outcomes sought are to increase and maintain quality of life for people with dementia, and to provide great peace of mind to the carer and family. • This is a very delicate area in terms of impingement of a person's civil liberties, and has to be very carefully balanced. Members then asked questions. The questions and answers are summarised below. **Does a family have to pay for these devices?** We are currently looking at how who would be responsible for paying. The scheme is very much in its infancy, and we are looking at available options. The 'Buddi' costs c. £400. The plain tracker costs c. £130. One of these devices can be monitored for £5 a month. Products are already widely available in the market. NRS also provide the devices. **If someone bought one of these devices, is there a contact centre?** We have a very small pot of funds for 'seek and find.' We need to find a cost-effective way of delivering a local service. We would like to trial this service and would suggest that the trial service be available to anyone with a need. The information would then be reviewed for BCC and the CCGs to make a decision, as to whether the service will be free to those who are eligible for social care, sold to self-funders or offered to anyone with a need at no / minimal cost. Members also said the following: • Carers Bucks had 6-8 'buddi' systems which they loaned to carers. • The gps devices were a great service which provided peace of mind for carers. • They needed to make sure that the devices were effective for people without a carer. • The Red Cross provided a service for those with a key safe but no carer (a 24/7 emergency response service). They were looking to extend this to 'seek and find' which would be paid for on a case by case basis. • The Red Cross had been called out 240 times in the previous year instead of an ambulance.
9	**Next Steps** Maxine Foster suggested that at the next meeting Board members could work to identify five clear aims which could be delivered over the following year. Christine Whiting asked for information about how each team connected to other teams. **Action: Structure chart showing what each team does to be circulated.**
10	**Date of the next meeting** **Date of the next meeting** 12 December 2014, 10am, Mezzanine Room 2, County Hall, Aylesbury 13 February 2015, 10am, Mezzanine Room 1, County Hall, Aylesbury

	AOB **Timeframes for funding** Christine Nash asked for more information on timeframes for funding on different dementia projects – **Action: More information to be provided on time frames for funding for dementia projects – add this to agenda for next meeting.** **Older People Representation** Pam Taylor said that there should be more representation at the Board from older people with dementia – **Action: More older people representation – DG** **Other important topics for discussion** • Importance of early identification and support – there was now a large evidence base about preventing / delaying dementia. It would be interesting to see how that linked into training. • Regarding memory-friendly awareness-training, Public Health had just let a contract around mental health first aid, and they could look to see if there were any synergies between the two. • Need to discuss a more holistic approach ('one stop shop'). • The Care Act will bring in requirements for robust information, advice and guidance - it is meant to be a 'one stop shop.' • Would like to see the Board making a difference on the ground. **Agenda items for February 2015 meeting:** • Action Plan in place to increase diagnostic rates by 2015 **ACTION: Olli to present** • Diagnosis of dementia for people with long-term conditions – how it can affect their medication. **ACTION: Seam to present** • Presentation of the Care Act - **Maxine**

Chairman