

Present:

		Action
<p>1.</p>	<p>Welcome and Apologies Angela Abbott, Catherine Butcher, Lynne Corner (Newcastle University), Corinne Walsh (South Tees Dementia Collaborative), Jim Lawson (North Tees Dementia Collaborative), Michelle Kindleysides (Beamish Museum), Sharon Tuffnell, Debbie Smith (TEWV), Jill Smith (HENE), Margaret Piggott (CRN: NE and Cumbria), Mandy Humes, Debbie Ainscow, Anthony Gonzalez (Essence Service), Gail Defty (Hospital of God), Susan Meins (North Tyneside Council), Christine Lowthian (NTW), Leon Mexter (YouthFocus NE), Karen Winspear (Skills for Care), Julie Daneshyar (PHE), Hazel Cuthbertson (Alzheimer’s Society), Madeleine Elliott (Years Ahead/AgeUK Northumberland), David Newman (NE SCN), Paul Johnson (NEMH DU), Roz Tinlin (RVS), Sharon MacInnes (Tyne & Wear Fire Service), Nigel Nicholson (NE Commissioning Support Unit), Ann Brown (NHCT)</p> <p>Apologies received from:</p> <p>Bob Nelson (Diagonal Alternatives), Sue Tiplady (Northumbria University), Moyra Riseborough (RRCA), Janice Clasper (Carer), Pauline Townsend (NTH), Alan Curry, Louise Allen, Vera Maw (Sunderland Carers)</p> <p>Chair: Lynne Corner until 11.30am</p> <p>It was agreed to discuss business items at the end of the meeting.</p>	
<p>2.</p>	<p>Regional Dementia Role</p> <p>Lynne gave a summary of the history of NEDA, how it has evolved over time and explained that the Regional Dementia Role undertaken by Debbie Smith had been fundamental to our work as a network. Lynne said that it was with great sadness that she was to announce that Debbie Smith was moving on to another role, but hoped that this would only be a temporary move. She presented a small gift and flowers on behalf of NEDA to thank Debbie for her invaluable support and contributions over the years. Lynne said that she hoped Debbie would remain an ambassador for dementia in the North East and play a part in the Dementia Innovation Hub.</p> <p>Debbie thanked everyone for the gift and wished everyone well in moving forward.</p>	
<p>3.</p>	<p>Knowledge Exchange</p> <p>LC reiterated the importance of sharing information and capturing the excellent initiatives going on in the region.</p> <p>Essence Service Presentation: Anthony Gonzalez</p> <p>Anthony gave an interesting presentation about the Essence Service which is a joint initiative between Age UK Sunderland and Sunderland Carers’ Centre funded by the Sunderland Clinical Commissioning Group.</p>	

The Essence Service offers a range of support services for people in the early stages of dementia for people resident in Sunderland who have a recent diagnosis of dementia with mild cognitive symptoms. Its main aims are:

- To provide individual support to people recently diagnosed with dementia and their carers.
- To keep as much of the 'essence' of the individual for as long as possible
- To enable people to live well with dementia for as long as possible
- To reduce the need for medical intervention GPs / A+E

The Essence service recognises the vital role of carers and we aim to support both the person with the diagnosis and any carers.

MP commented that people go to memory protection services and get a MCI diagnosis but often feel set adrift with little support. She informed the group that the Memory Protection Service is now offering a telephone engagement service. At the point of diagnosis many people feel too overwhelmed by the impact of the diagnosis to think about their support needs. The new telephone service will keep people in the loop and so they may be referred on to support services at a later date as needs arise.

AG advised that the Essence Service is seeking to widen its remit to support people at pre-diagnosis and is currently building a business case, using its evidence base, to get this service commissioned.

A discussion ensued about the Strategic Clinical Network's efforts to develop a pre-diagnosis pathway. Currently clinical commissioning is unable to provide support services to people without a diagnosis so this is a positive move forward.

The group discussed the challenges of capturing outcomes. AG said he found outputs easier to collect but Essence services has been building its own evidence to support the outcomes, (e.g. attended training = resilience outcome). It is difficult for someone with dementia to use standardised outcome measures and there is a need to look at other ways of measuring outcomes. This may be an area of work that the Dementia Hub could take forward.

PHE Dementia Risk Reduction Presentation - Julie Daneshyar

Julie presented the recently published Public Health England Dementia Risk Reduction Guidance which provides an overview of approaches that may help to delay or prevent onset of dementia.

The report acknowledges that the risk of dementia, disability and frailty will sometimes be determined by factors that cannot be changed e.g. inherited conditions, but illustrates that by changing specific risk factors and behaviours the risk of dementia, disability and frailty can be reduced for many people. Evidence suggests that smoking, drinking, high blood pressure, lack of physical activity and diabetes all contribute to higher risk.

A reduction in incidence and prevalence of dementia in 65-75 year olds may be achieved by promoting and measuring behaviour change at 40- 60 years. The overall aim is to delay the onset of dementia and increasing the amount of time that people can be independent, healthy and active in later life. These changeable factors are for example: smoking, lack of physical activity, alcohol consumption, poor diet and mental wellbeing.

The guidance will be accompanied by a common sense campaign and dementia risk reduction will form part of wider public health message.

	<p>The group discussed possible links to social deprivation and the need to ensure that the message is not interpreted as white middle class professionals talking to other white middle class professionals. They also discussed the difficulties that Local Authorities may have in taking the lead on this campaign as pressure increases on their budgets.</p> <p>JD: Asked how do we get these messages across into treatment services? E.g. Essence service – how do they talk about lifestyle changes to their clients e.g. alcohol. The group discussed whether it was possible to identify ‘teachable’ moments to pass on these messages.</p> <p>DS reported that TEWV are addressing some of the messages and are currently looking at smoking in the Mental Health Services.</p>	
4.	Focus on: Dementia Innovation Hub - Establishing a functioning and purposeful evidence base	
	<p>AA and CB gave a short presentation focussing on:</p> <ul style="list-style-type: none"> • Introducing the Hub Website • Using NEDA networks to generate web content in response to current and emerging trends/needs, e.g. case studies. <p>During the presentation the Dementia Hub team outlined plans for the development of a functioning and purposeful evidence base and explained how NEDA members and other partners could have a role in promoting and sharing reports/information.</p> <p>NEDA members are invited to submit guest blogs to be uploaded to the website. The blogs will provide an opportunity for members to reflect on the work they’re doing, discuss an issue from different perspectives or even describe a particular ‘bug bear’ within the field of dementia. The Dementia Hub team will retain an element of editorial oversight. The website will also include a ‘share your experience’ button which will be used to gather experiences and case studies for the evidence base. Lynne suggested that the Hub will serve as a repository for dementia information from International, national, regional and local perspectives.</p> <p>In response to a question about a discussion forum for NEDA, Lynne explained that this hasn’t yet been set up but explained that there is discussion forum via Voicenorth. She reiterated that Dementia Hub should be viewed as an honest independent broker and that people should feel confident about using the website to challenge and asking difficult questions. It was acknowledged that some members may have restrictions on what they can say when representing their organisations.</p>	
5.	Future NEDA Meetings	
	<p>CB introduced a paper about themes of future meetings and stressed that the style, content and structure of future NEDA meetings should be driven by its members. Suggested themes include:</p> <ul style="list-style-type: none"> • Advanced dementia, incontinence, and other more difficult areas. • Outcomes star – (Scott – Mental Health Concern) • Look at other sectors and how they measure. • Advanced dementia and carers needs <p>CB asked if anyone would be willing to take part in a working group to identify future meeting themes, and structure and asked people to contact her directly.</p>	
6.	Launch of the Dementia Friendly Stations Video	
	<p>Members were given a preview of the Dementia Friendly Stations video which was due to be launched at Newcastle Central Station later in the day. The video was funded by the Dementia Hub and Virgin Trains East Coast.</p>	

	The video is available to download https://www.youtube.com/watch?v=pUu9Tqn3E5g . A small supply of DVD copies of the video will be available from the Dementia Hub and British Transport Police.	
7.	Government Mandate to NHS England	
	<p>DS explained that a consultation document had been published which sets out how the government proposes to set the mandate to NHS England for this Parliament. The final mandate will be subject to the outcome of the government's Spending Review. The mandate sets direction for the NHS, and helps ensure the NHS is accountable to Parliament and the public.</p> <p>In accordance with the Health and Social Care Act 2012, the Secretary of State must publish a mandate each year, to ensure that NHS England's objectives remain up to date. The new mandate to NHS England is due to be published following the completion of the Spending Review, to take effect from April 2016.</p> <p>DS asked if we should submit a response on behalf of NEDA in addition to our own organisation responses. All agreed that this would be acceptable. The main area that NEDA agreed to comment on was the priority 'Transforming out-of-hospital care, ensuring services outside hospital settings are more integrated and accessible'. The focus on integrated services and care agenda affirms the need to improve quality of life of people with long term conditions but this will require implementing quality services through good commissioning. However, there are also a number of gaps in this priority:</p> <ul style="list-style-type: none"> • Carer gap throughout the document • Reference is made to a health gap but this should be a priority in its own right rather than included in hospital care. • The use of the term 'care' may be misleading. Social Care should be used instead which also implies wider organisational input. • Definitions of care should be included in the document. • Reference to 24/7 access to GP and hospital care. Unclear if these services are equipped to respond to the potential increases in demand. Question whether the mandate is pushing too far. <p>NEDA members were invited to send any further comments to CB by 23rd November, who would then collate a response from NEDA.</p>	All
8.	Members Updates	
	<p>The following reports were presented for information:</p> <ul style="list-style-type: none"> • Members update • Alzheimer's Society Update <p><u>SCN: Dementia Pathways update</u></p> <p>DN presented a summary of the work being undertaken by the SCN to develop a Dementia Pathway. This work originally arose from feedback at a regional event for interested stakeholders run by the Northern England Strategic Clinical Networks & NEDA. The delegates felt that there was a lack of a clear pathway for suspected or confirmed dementia that is well and widely understood.</p> <p>We gathered some key stakeholders to address this need. They agreed a Terms of Reference to create a 'blueprint' based on two key principles.</p> <ul style="list-style-type: none"> • Early, needs based support for people with suspected or confirmed cognitive disorders and their carers to maintain wellness. • Integrated health, social and third sector working. 	

	<p>Key achievements to date:</p> <ul style="list-style-type: none"> Grown the group membership to widen representation and had three meetings. Gathered and reviewed existing pathways and related documents from this region and elsewhere. Investigated potential measures for the pathway. Process mapped a current typical case of what happens now. Linked into national developments in the NHS. Drafted a communications strategy. <p>The next step is to design an engaging blueprint (to 'market' the principles) using a disruptive design process, supported by Northumbria University. This will be developed with other elements from the terms of reference which are, a menu of interventions based on good practice and a realistic commissioning 'guidance'. Beyond that we'll be looking to test implementation in a local area.</p> <p><u>Tyne & Wear Fire Service</u></p> <p>SI reported that there is a new national requirement for the Fire Service to carry out health and social care safety checks. The 'safe and well' visits will require Fire Service personnel to assess for general health and wellbeing, and to flag any concerns about frailty, falls and dementia. The aim is for the Fire Service to be classed as a Dementia Friendly Community.</p> <p>SI stated that Tyne & Wear Fire Service would welcome support from NEDA on the conversations needed and referral pathways. Some funding is being sought from the Police Innovation Fund to train frontline staff. Further work is being undertaken to develop a reporting mechanism via the Blue Light Challenge. Sharon offered to give a presentation about the project at a future NEDA meeting.</p>	
9.	Minutes of Previous Meeting	
	Agreed. No matters arising.	
6.	Any Other Business	
	No further business.	
7.	Date, time and venue of next meeting	
	<p>Date: 21st January 2016</p> <p>Venue: YouthFocus NE, 6, New Century House, West St, Gateshead NE8 1HR</p> <p>Theme: Young people and Dementia</p>	