Norfolk Older People's Strategic Partnership (NOPSP)

Edwards Room, County Hall, Martineau Lane, Norwich

Thursday 7th March 2019

(Abbreviations: STP = Sustainability and Transformation Partnership, NCC = Norfolk County Council; CCG = Clinical Commissioning Group; DC = District Council; NOPSP = Norfolk Older People's Strategic Partnership)

Present:

David Button	NOPSP Chair
Mary Ledgard	Norwich Older People's Forum (Vice Chair)
Carole Williams	Norfolk Council on Ageing (Vice Chair)
Erica Betts	Breckland Older People's Forum (Vice Chair)
Penny Carpenter	Great Yarmouth Borough Council
Verity Gibson	Norwich Older People's Forum
Sue Whitaker	Norfolk Council on Ageing
Hilary MacDonald	Age UK Norfolk
Joyce Hopwood	NOPSP President
Dan Skipper	Age UK Norwich
Nikki Park	NCC Transport
Janice Dane	NCC Adult Social Care
Derek Land	Norfolk Council on Ageing
Haley Griffiths	Norfolk Constabulary Mental Health Lead
Ruth Stannard	South Norfolk Older People's Forum
Judith Berry	Careline
Rebekah Bensley-Mills	LILY

In Support:

Janine Hagon-Powley	NOPSP Support Officer
Tasha Higgins	Community Action Norfolk (CAN)

Apologies:

James Bullion	Early Help and Prevention, NCC
Lesley Bonshor	Carers Council Norfolk
Craig Miller	Norfolk Constabulary
Tracey Fleming	NNUH
Graham Creelman	Chair of the Norwich Cultural Partnership
Hilary Sutton	Broadland Older People's Partnership
Sheila Young	West Norfolk Older Persons' Forum
Laura McCartney-Gray	Norwich Clinical Commissioning Group

Speakers:

Michael Hornberger (Chair of Norfolk & Waveney Dementia Partnership, Professor of Applied Dementia Research at University of East Anglia)
Willian Snagge (Transformation Manager for Mental Health and Learning Disabilities in Norfolk, South Norfolk CCG)

1. Welcome

[1]David Button welcomed everyone, thanked them for coming, led the introductions and shared his personal thanks to Graham Creelman, who has sent his apologies, for his work as the previous chair and in compiling NOPSP's new strategy.

2. Minutes and Matters Arising

[1]The minutes of the meeting held on 29th Nov 2018 were agreed as a fair record with the following amendment:

- Apologies – amend spelling of surname to Whitaker.

[2]Carole Williams reported a very positive and useful meeting with some members of NCC's Digital Contents Team, for which an update was circulated with NOPSP members. There were several points where they agreed to go away and consider what they might be able to do to improve various aspects of NCC's website. One of the team offered to speak at a future NOPSP meeting to explain some of the work they do, which might be very useful.

3. Dementia

[1]David Button: Dementia has not been selected as a priority in the new strategy mostly because it is such an overwhelming and overarching topic for older people. A good deal of progress has been made in dementia awareness, including training and getting businesses and services more aware of how to treat and work with people who have dementia and their carers. Terry Pratchett wrote "The Baby Boomers are getting older and will stay older for longer and they run right into the dementia firing range. How will a society cope especially a society that can't so readily rely on those stable family relationships that traditionally provided the backbone of care."

[2]David Button introduced Michael Hornberger who shared an update on dementia research. The following key points were raised in the presentation:

a) Doing a lot of work with the STP, Norfolk and Suffolk Foundation Trust (NSFT), Norfolk Community Health and Care (NCHC), hospitals etc.
b) Dementia is now the third most common disease in ageing, after heart disease and stroke. Cases of dementia are projected to double, if not triple over the next 40 years with dementia rates increasing globally and locally.
c) Dementia is an umbrella term under which there are several different diseases. The most common is Alzheimer's disease followed by vascular dementia which together account for > 70% of cases. Very often people don't recognise the rarer forms of dementia and GPs struggle to diagnose them.
d) Alzheimer's disease is caused by the accumulation of proteins in the brain which start clumping together, becoming toxic to nerve cells and is a progressive disease with high mortality. Majority of people will be over 65 years old; however up to 25% of people can be younger than 65. Genetic cases, i.e. a strong family history is very rare < 1%.
e) Vascular dementia is a stepwise deterioration, i.e. people maintain the same level of functioning for some time before deteriorating, therefore when people

come to a clinic their brain is already full of proteins and seeing them far too late – how do we identify them earlier? Vascular dementia is related to your cardiovascular health and risk factors include hypertension, diabetes, arteriosclerosis, diet, smoking, alcohol. That's why there is a mantra of what's good for the heart is good for the brain because it can reduce your vascular risk very significantly.

f) The difference between Dementia and Alzheimer's disease still confuses a lot of people. A recent survey of people's perception of dementia by Alzheimer's Research UK highlighted that although most people know that dementia is not part of normal ageing, 39% were unsure or unaware. Therefore, need to continue to promote the message that dementia is a disease that we need to treat or prevent. The survey also highlighted that younger people (15-34) seem to be doing worse than older people at knowing what is happening in the brain.
g) The costs of dementia to society are enormous and the majority of costs (£11.6 billion) are carried by unpaid carers. The cost of dementia in the UK is expected to more than double in the next 25 years, from £26bn to £55bn in 2040.
h) The government's idea is that ideally people live longer and healthier at home but it's a struggle as many people, especially when they have other incidents for example falls, very often get a dementia diagnosis which then triggers a cascade of care.
i) There is now a huge push towards prevention, research around post diagnosis (helping and treating people at home), as well as a shift from the patient towards the carer and family, because its been recognised that they carry the burden of everything therefore how can they be supported better.
j) Very often services for people with rarer forms of dementia, which are very often early onset (under 65), are much poorer and under recognised in dementia services.
k) Pharmacological treatments have been a disaster to date. In earlier survey, 50% of people feel that treatments so far are not effective and 22% are unsure. 27% of people prioritise research for a cure followed by 26% prioritising research for ways to prevent the disease. Currently there are only 5 symptom treatments approved worldwide for Alzheimer's disease. Combination therapy is needed, as 2 proteins involved, but it takes approx. 12.5 years to develop a new drug and around £1.15bn so pharmaceutical companies need to invest a lot of money. Lots of companies have tried and failed and are pulling out of dementia as losing too much money, yet patient numbers increasing. There is one treatment in Phase 3 trials worldwide and is the only drug so far which seems to slow down the build up of proteins.
l) Lack of treatment options led to focus on genetic and environmental factors such as vascular prevention to reduce risk or delay onset. In survey only 34% knew risk factors for dementia compared to 52% cancer and 81% diabetes. 25% don't want to be diagnosed linking to perceived lack of post diagnostic support.
m) Nearly all the modifiable risk factors are relying on lifestyle change; the notion what's good for your heart is also good for your brain. Regular physical activity reduces your risk of dementia by 30% and hip fractures by 68%. 75% of people are unaware that they can affect their risk of developing dementia.

n) Public Health England has a role in reducing the risk of dementia by developing and enforcing strategies related to tobacco and alcohol consumption, physical activity, healthy diets, loneliness and cognitive and social activity. However much of this is about habit changing which is tricky.
o) Take Home Messages – Pharmacological treatments are coming but will only slow down the disease and you can reduce your risk of dementia by 30% via lifestyle factors.
p) Bi Monthly Dementia Open Forum where UEA researchers present their studies and findings with next forum on 17th April 2019. One UEA research project is looking at how the 'Mediterranean diet' can be integrated into the UK diet.

[3]David Button thanked Michael Hornberger for his presentation. The following points were raised during the subsequent discussion:

q) Occupation is not really a factor what is much more important is how much education you have in your childhood and how mentally active you are throughout your life e.g. playing a musical instrument.
r) Seeing a big shift towards touch screen technology as although people in their 80s are less accustomed to technology, people in their 60s/70s are much savvier these days. For the home environment there are a lot of privacy implications around technology, particularly homes with or at high risk of dementia, and technology is therefore much more of an ethical question rather than a practical one now.
s) The ability of young people to understand components of food and cooking has diminished following school curriculum changes which has not helped reducing risks associated with lifestyle factors e.g. salt intake, portion size, physical activity, intake/output and should be pushed at government policy level.
t) Memory gets naturally worse with ageing especially after 85 and therefore diagnosis after this point is tricky. The older you are, the more likely you are to develop dementia. However, dementia is not an inevitable part of ageing. If you focus only on memory you will only detect the disease at its later stage/s. For earlier diagnosis it is important to observe changes in people's daily activities, behaviors and approaches over time but how can this be standardised as at the moment it is a short-term assessment.
u) Memory is a very sensitive but unspecific symptom with a lot of research happening around specific symptoms for each type of dementia. Large screening programmes tend to generate many false positives as assessment is over a relatively short time frame.
v) Some carers are much better at coping following a dementia diagnosis than others and there is a UEA project looking at training around this.

[4]David Button introduced Willian Snagge who provided an update on the organisation and operation of dementia services. The following key points were raised in the presentation:

a) Following the STP Dementia Support Review they are beginning to establish a series of task and finish groups.
b) The NHS Well Pathway for Dementia outlines the key steps from prevention to diagnosis, post diagnostic support and end of life from the perspective of a

patient or carer and was used as a framework when thinking about the review and what the system could do differently at each point of the pathway to improve services, support and prevention.

c) The key issues identified at the beginning of this review were late identification to get support and planning in place, system coordination, perceived shortage of post diagnostic support, community capacity and its role in providing support, support in care homes and home care, workforce and training.
d) There has been engagement with professionals, stakeholders, patients, carers, organisations and communities as well as best practice elsewhere.
e) There is a link between people's appetite for a dementia diagnosis and people's perception of post diagnostic support.
f) The review to date has told us that we need to do;
   - More to promote independence and prevention,
   - More around diagnosis - making it more accessible, timely and closer to home,
   - More around support - how it happens and how joined up it is,
   - The importance of peer support and how the system needs to do more to promote good quality peer support,
   - More around workforce training and building the workforce across the system recognising that the system is constantly changing especially with the emergence of Primary Care Networks (smaller population-based clusters delivering more services closer to home) and therefore need to consider how all this work fits and aligns with that.
   - Need for good post bereavement carer support.
g) Therefore looking at the development of new models and approaches to diagnosis (more accessible and faster), multiagency highly collaborative primary care facing tier support (a support service which you are referred to at point of diagnosis that is aligned with local communities, with a central hub that supports patients and carers along the pathway), community development including community assets, collaboration with Public Health and the wider prevention agenda and working with the Healthy Ageing community and independent organisations.
h) The four building blocks to make this happen are focused on;
   - Education and training,
   - Effective diagnosis,
   - Joined up and accessible support for patients and carers,
   - Peer and wider community development.

   With the overarching themes of communication and pathway development to help people navigate through services. Keeping accessible and local as well as having a central point of contact.
i) The task and finish groups, meeting roughly monthly, are now working up more detailed plans, talking to other people in the system, making business cases, making sure the evidence is there.
j) A lot of this is about using resources differently or smartly although in the support zone there is a recognition across the system that there is also a need for more resource.
k) If anyone would like to get involved in these working groups email dementiareview@nhs.net

[5]David Button thanked Willian Snagge for his presentation. The following points were raised during the subsequent discussion:

a) There is a lot of training available, so it is about making sure it is all being delivered to a certain standard ensuring consistent messages.
b) Need to have people on these groups who have direct experiences of pathways and processes 'on the ground' as need to consider the simple things of who does what, how they do it etc. as well as the higher-level strategy and service development. Also need to measure what goes wrong to inform future improvements.
c) Carer/ family members can be reluctant to even go to GPs etc. as they don't want to upset person with dementia and therefore there are a lot of hidden and hard to reach who are sometimes struggling the most.
d) The absence of assistive technology and its value and role for both patients and carers (Durham case study). Norwich Dementia Hub has identified assistive technology particularly as something they might want to do more around.
e) LILY has been working with West Norfolk CCG on a short-term dementia awareness project which runs to the end of March 2019 targeting GP practices with lower diagnosis rates as well as individuals themselves to try and break down barriers to being diagnosed.
f) Potential challenges and tensions between new national drive around localisation and PCN orientated delivery and more strategic system wide planning and delivery.
g) Given workforce challenges can labour intensive services be resourced effectively? Need to find a way of recognising the value of the workforce differently and making a career in care being something people can aspire to.
h) All 7 district councils have recently agreed that as of next year they will come together to provide a non-means tested dementia grant.

4. "Living Longer Living Well" Strategy 2019-2021

[1]David Button introduced the final draft of the "Living Longer Living Well" Strategy 2019-2021, which is important as it is derived from what older people tell us. Given NOPSP's resource constraints we are looking to make the strategies role and purpose a bit more dynamic. Therefore, we will be sending a letter to all the organisations that we citied as being accountable for the previous strategy to try and find out progress on each theme, in terms of influence and change, providing a benchmark for the next strategy.

[2]We have been in negotiations with Archant publishers to try and create a way for all members of the NOPSP, and others if relevant, to be a lot more transparent and accountable directly with the public. The idea being that we will have a monthly newspaper article/page in the EDP, and probably other articles, where either we as a partnership or individual organisations can present an article about something that would be interesting and informative for older people. A retired journalist is prepared to give some of his time to create a style and provide editorial support. The content will not exclusively be about older people, for example intergenerational, rather whatever is appropriate and relevant. This will keep us in the limelight routinely and regularly which seems to be important. Our role will be providing readable, engaging, informative, relevant and important to the public, enabling what's on,

signposting and sources of information etc. to be repeated and for us to share what we are doing. Apart from the retired journalist there are no resources behind this proposal, so its success depends on all of you. This is a start on trying to make NOPSP more understandable, in the public face and accountable to older people.

[3]Hilary MacDonald asked whether this could be used for campaigning. David Button agreed as no specific restrictions have been stated. What it isn't going to be is dry, dusty press releases.

[4]David Button confirmed that this is a final draft and looking to get the strategy signed off today and printed around end of April.

[5]Sue Whitaker suggested the following amendments:

- Adding column headings on each page and making these either in bold or italic print.
- Removing the apostrophe from CCG's.
- Consistency of capitals/lower case regarding NCC and Public Health.
- Clearly defining 'The Partnership' in the main introduction to avoid any confusion when stated in 'Lead Agency/ies'.

[6]Dan Skipper asked if there was a reason why there isn't anything about access to welfare and eligibility. David Button responded that this is an overarching theme that will be referenced to in the strategy's overall introduction.

1. **Information and Advice**

[1]Carole Williams commented that this continues to be an anchoring theme and tries to include the changing nature of the health and social care landscape, by using the term Local Delivery Groups, but does worry that within a few years' terminology might have changed again. David Button agreed that the problem of terminology will remain and evolve what we can do within the strategy is be consistent.

[2]Comments:

- Add Borough Councils to 1.2 Lead Agency/ies.
- 1.3 – add social isolation after 'pioneering social prescribing' given its role in information and advice.

2. **Transport**

[1]Comments:

- Introduction second line – amend 'affect'.
- Introduction first paragraph – (ICS) initials are included but not STP Sustainability and Transformation Partnership which would allow abbreviation in 2.1 Lead Agency/ies.
- 2.2 – Change to 'Refreshed Norfolk Local Transport Plan'.
- 2.4 – Add NCC to lead agency/ies.

[2]Regarding 2.3 Nikki Park commented that she does not see how having a transport black spot map is a success and what this is trying to achieve. Erika Betts

responded that the emphasis should be on seeking to solve the problem/s identified by the map which isn't reflected. Nikki Park added that she doesn't think the lead agency/ies can commit to producing a black spot map on a regular basis as we have our own target levels of service that we have to report massively on for example if you are a parish with 100 people you should expect this level of service, which is how we base funding decisions. With no more money in the system not going to solve black spots and therefore reduces its purpose as no guarantees.

[3]This was followed by a discussion around the deliverability of this objective and availability of transport services generally.

[4]It was agreed that 2.3 would be deleted and amendment made to 2.4, under 'What success looks like', stating that where there are identified gaps lead agency/ies will look to see if there are any solutions.

[5]Regarding 2.4 Nikki Parks highlighted NCC's lack of control in making a 'coherent network of community transport operators' given the sectors diversity and therefore not sure what the expectations are. Erica Betts suggested amending wording to 'work towards a coherent …' which all organisations can then aspire to.

[6]During the discussion Nikki Parks clarified that there are criteria for the Transport Plus service including mobility questions and as a volunteer led service it is based on the availability of volunteer drivers and therefore do sometimes have to turn people down.

[7]Carole Williams highlighted the difficulties in regard to people finding transport information particularly on statutory websites.

[8]Hilary MacDonald suggested inviting Nikki Parks to present at a future meeting of NOPSP under a transport theme which would be very useful.

3. Housing

[1]Comments:

- Change 'BT and other broadband providers' to just broadband providers.
- Amend 3.1 'What success looks like' second sentence - To minimise isolation and offer inclusion to people with physical and mental frailties their needs should be reflected within strategic and local plans.

4. Loneliness and Isolation

[1]Comments:

- Introduction second paragraph – add social isolation to sentence reading 'Recent pilot initiatives have been launched in Norfolk to help, such as Social Prescribing and Social Isolation.'

5. Integration of Health and Social Care

[1]Comments:

- 5.2 – change phrase ‘wrap around’ to fit around.

6. End of Life

[1]Comments:

- Introduction second line change from ‘People living with palliative treatment’ to People living with a palliative diagnosis’.
- 6.1 – add asterix after Yellow Folder and add a glossary definition/explanation for ReSPECT.
- 6.2 – Change ‘Age UK and other voluntary organisations’ to just voluntary organisations.

8. Any Other Business

Fruit was requested at the next meeting.

David Button thanked everybody for their contributions.

The meeting ended at 13:00.