

CPG on Dementia Meeting Notes – 21/03/23

Attendees:

Jayne Bryant MS; Laura Braithwaite Stuart; Sian Gregory; Sion Jones; Huw Owen; Charlotte Knight MSSS; Ryland Doyle MSSS; Ceri Higgins; Andy Woodhead; Nigel Hullah; Valerie Billingham; Tracey Williamson; Ioan Bellin MSSS; Sarah Elliott; Rhian Russell-Owen; Kathryn Morgan; Judith John; Jon Matthias; Ian Dovaston; Lilli Spires; Catherine Charlwood; Catrin Hedd Jones; George Parish-Wallace; Heather Wenban; Katherine Lowther; Lowri Morgan; Lowri Williams; Oliver John; Suzy Webster

Apologies: Delyth Jewell MS, Peredur Owen Griffiths MS, Llyr Gruffydd MS, Chris Roberts and Jayne Goodrick, Claire Morgan, Neil Mason, Rebecca Cicero, Alison Johnstone, Monica Bason-Flaquer, Helen Cunliffe and Dr Rosslyn Offord.

Introductions

SJ welcomed everyone to the meeting and asked attendees to introduce themselves via the chat box. SJ introduced JB to Members, who is vice chair of the CPG.

Presentation on the Allied Health Professionals Dementia Framework for Wales: *Laura Braithwaite Stuart, Specialist Speech and Language Therapist, Betsi Cadwaladr University Health Board, Doctoral student Bangor University*

JB introduced LBS to Members. LBS explained how the framework was completed during a secondment with HEIW. LBS spoke about AHPs and how there is a difference across different countries in terms of who is recognised as an AHP. In Wales, Allied Health Professionals (AHPs) are 13 individual professions regulated by the Health and Care Professions Council (HCPC).

LBS spoke about the 12 month leadership project to develop an evidence-informed framework to maximise the impact of Allied Health Professionals (AHPs) working with people living with dementia and their carers. There had been no previous formal review of AHP services supporting people living with dementia and their carers in Wales. LBS spoke about the importance of ensuring that the framework complimented the vision of other key pieces of documentation, including the Dementia Action Plan and the All Wales Dementia Care Pathway of Standards, ensuring that meaningful co-production was embedded throughout.

LBS spoke about the aims of the Framework, which are:-

- **Define the contribution and offer of AHPs** in supporting people with dementia to keep doing the things that matter to them, as well as wider population health throughout the life course
- **Present the current evidence** in relation to findings from scoping literature review and emerging practice regarding the impact of AHPs in dementia care and in supporting those at risk of dementia
- **Serve as an evidence-based resource that can be called upon to support influencing work**, from service level to policy level, cross-cutting through all parts of the care pathway
- **Act as an accessible document**, comprehensible to both professionals and people with dementia and families

LBS mentioned that the direction of the framework had been expertly supported by a steering group of people living with dementia, their carers/supporters, AHPs and a number of different partners

and stakeholders. Connecting with people living with and effected by dementia is so important- Alzheimer's Society's Dementia Voice and TIDE have supported this.

The framework looks at a whole system tiered approach to care and support, not just for those in dementia-specialist services. Dementia is everyone's business. At an universal level, this looks at people living with dementia being able to engage in activities to support them within communities before necessarily accessing services.

The targeted level looks at AHPs supporting the learning of others to be able to carry out best practice. Different methods in terms of learning person-centred training and development.

The specialist level looks at interventions which are led by AHPs, so that they're tailored for the needs of the individual.

LBS spoke about the importance of language, and that the glossary was co-produced with the steering group. The document focusses on the individual person.

The Framework sets out quadruple priorities to transform AHP care in dementia:-

- 1) **Increasing Awareness and Access to the AHP approach,**
- 2) **Increasing Innovation and Improvement**
- 3) **Co-production and collaboration**
- 4) **Leadership and learning**

Calls to action are listed within each theme, and expected outcomes to support measurement of what has been achieved.

LBS mentioned that the framework was launched on 14th October 2022, and that there is an individual and collective responsibility to enact. Framework has been presented in a number of forums, and are available on the Welsh Government website.

AW mentioned the importance of continuous funding for this work. Change of culture is so important, but funding does have a part to play. CH mentioned that being involved in the work was empowering and that the term AHP is often misunderstood. Public awareness is important- you don't know what you don't know. TW said that it is now up to all of us to ensure that this work is promoted and shared widely.

Research and Dementia: Update on lecanemab: *Siân Gregory, Research Information Manager, Alzheimer's Society*

JB introduced SG to members. SG began by talking about Alzheimer's and dementia- Alzheimer's disease is characterised by the build-up of two proteins, **amyloid and tau** in the brain – thought to be toxic to brain cells. Alzheimer's Society funded seminal research which was the first to show amyloid played a role in causes of Alzheimer's disease. Amyloid hypothesis is the basis of how lecanemab and donanemab work. SG mentioned that lecanemab and donanemab belongs to a family of drugs called immunotherapies. Immunotherapies are used in cancer and asthma, and researchers have designed special antibodies which target amyloid in the brain, referred to as disease modifying treatments: treatments which can slow down progression of disease. News from phase 3 trials of donanemab expected **in first half of 2023.**

SG mentioned that lecanemab had been tested in people with early Alzheimer's disease- data released in November 2022. Lecanemab treatment shown to slow down how quickly thinking and memory skills get worse **by 27%**. This means that it's slowed down Alzheimer's disease from getting worse by a potential of about **7 1/2 months**. The findings also showed a reduced loss of quality of life by up to 56%. Lecanemab had effectively removed amyloid protein from the brain by end of the trial. More data to come, but this is a momentous big step- Science has never been able to show that we can slow down a disease that causes dementia before.

There were side effects from lecanemab- majority due to intravenous method of giving the drug and some brain changes we see in the brain when using amyloid targeting drugs like lecanemab. These brain changes can be localized, swelling or they can be microbleeds, and these did occur in the trial. These will be evaluated when the drug is submitted for approval – a drug won't be approved in Europe unless it is both safe and effective. Lecanemab not available in UK yet – would need approval by MHRA (UK regulatory body). SG emphasized that lecanemab is only available for people with early Alzheimer's disease- not available for people in later stages. It also won't benefit people with other types of dementia. However, now that it has been shown that it is possible to slow down progression, continued research will discover more possible treatments.

SG mentioned that early detection and diagnosis is key. Disease modifying treatments are believed to be more effective the earlier they are given. Even if treatments like lecanemab become available, late diagnosis could make them inaccessible to people living with Alzheimer's disease. Because lecanemab targets amyloid protein – it's presence in the brain would need to be confirmed at diagnosis for a person to access it as a treatment. A person would need a specific diagnosis, rather than a more general diagnosis of dementia. Two techniques:-

1. PET Scanning
Number in UK is low- 3 in Wales (Cardiff, Swansea and Wrexham)- predominantly used for cancer
2. Cerebrospinal fluid testing
Requires lumbar puncture. Not routinely used in UK memory clinics. Research has shown it to be cost effective and safe- used more widely in Europe.

CH asked about language, and how a focus has moved from 'cure' to 'slowing down'. CH also mentioned that it is important not to invalidate people's feelings- people must not be made to feel that they have the 'wrong' type of dementia as these drugs might not benefit them. CH also asked about vascular impact of side effects. SG mentioned that we are absolutely still working towards a cure. Highlighted the importance of not giving false hope to anyone. Treatment starts with looking to slow down diseases- spoke about how this was the case with cancer. SG mentioned that majority of micro-bleeds were asymptomatic, and impact of side effects is still being examined.

NH spoke about the work which pharmaceutical companies are doing in the field, and how much this is developing. False hope should not be given, however this research is incredibly advanced. AW mentioned that there are some types of dementia which are linked to lifestyle. Important to look at all aspects.

Date of Next Meeting

May or June 2023