

CPG Meeting Notes – 09/11/22

Attendees:

Heledd Fychan MS; Lynne Neagle MS; Sion Jones; Huw Owen; Amanda Whent; Ceri Higgins; Andy Woodhead; Nigel Hullah; Valerie Billingham; Versha Sood; Lilli Spires; Ollie John; Karyn Davies; Rebecca Cicero; Melanie Sillett; Helen Cunliffe; Michaela Morris; Rebecca Hanmer; Catrin Hedd Jones; Joe Gape MSSS; George Parish-Wallace; Heather Wenban; Jake Smith; Katherine Lowther; Kevin Duff; Rhys Livesy; Lowri Morgan; Lowri Williams; Pdraig McNamara; Melanie Sillett; Oliver John; Suzy Webster; Sally Thompson; Monica A Bason-Flaquer

Apologies: Peredur Owen Griffiths MS; Llyr Gruffydd MS; Rhun Ap Iorwerth MS; Delyth Jewell MS; Dr Rosslyn Offord; Helen Twidle; Sue Phelps, Dr Catherine Charlwood

Introductions

HO welcomed everyone to the meeting and asked attendees to introduce themselves via the chat box. HO explained to Members that there would be a temporary chair for this meeting of the CPG, and that HF had agreed to chair the meeting. HF introduced herself and gave an introduction on her work as the MS for South Wales Central

Update from Deputy Minister for Health and Wellbeing, Lynne Neagle MS

HF introduced LN to the meeting. LN thanked the group for the invitation to attend, and told members that she was pleased to be able to provide an update on WG work around dementia. LN mentioned that the implementation of the Dementia Action Plan supports a clear rights based approach and to ensure that care and support for people living with dementia is person centred. A key focus of this work has been the dementia care program, supported by Improvement Cymru, and developing the All Wales Dementia Pathway Standards, which supports a whole system integrated care approach. The Standards were developed over a two year period, with input from over 1800 stakeholders. Crucially, and most importantly, this included those people living with dementia and their carers through to voluntary sector organizations and practitioners across Wales and the UK.

LN spoke about the work streams which have been established to support this work, These are community engagement, memory assessment services, dementia connector, Hospital charter as well as a fifth work stream. The financial year we're in is currently being seen as a readiness period for implementation, with a focus on supporting regional leads in understanding the Dementia Pathway Standards and delivery framework approach.

LN spoke about the CPG's report on hospital care in Wales, and thanked the CPG and Alzheimer's Society Cymru for their work in producing this. LN mentioned that she was pleased to have played a part as the previous chair of the CPG. LN stated that the report contains a really strong insight into dementia care and hospital settings, and was tabled for discussion at the DOIIG meeting at the end of September, where the findings were discussed in detail.

LN spoke about the launch of the Dementia Friendly Hospital Charter for Wales, emphasizing the way in which the charter was co-produced with people affected by dementia. The Charter will be vital in supporting people when they need care within a hospital. How people are engaged, empowered, enabled and cared for is crucial in providing a positive hospital experience.

LN mentioned that Improvement Cymru have been asked to ensure that when working with partners as part of this work, they are asked to focus on areas which the CPG has identified in the report on Hospital Care in Wales, and would be happy to share progress as this develops.

The pandemic brought about an urgent need for us to rethink the way our services operate, whilst understanding how to deliver the care required for people to live the highest quality of life. The DAP companion document was published in September 2021.

LN spoke about an increased pressure on memory assessment services. To support this, £3 million was allocated from 2021 to 2022 to regional partnership boards to support people through the assessment process and following diagnosis. This is in addition to the £9 million allocated with the DAP to develop a joint health and social care approach to dementia support, representing a significant increase in funding. The impact of this funding is being closely monitored.

LN mentioned that WG have commissioned an independent evaluation into the DAP, which is continuing to assess its impact on dementia care and support in Wales. The pandemic has had an impact on this, and the work is expected to continue into 2023, and will inform the successor arrangements. The Welsh Government are committed to working with the CPG and other key partners to develop the successor plan.

AW mentioned that he was proud of what is happening in Wales, but emphasized the impact of the care crisis, including rate of pay and lack of value and respect for the sector. LN acknowledged that the financial pressures are immense.

CH raised the impact of the pandemic on unpaid carers, and mentioned the new report from Carers Wales, as well as the importance of lived experience. We don't know the real impact today on unpaid carers caring for people with dementia, especially with consideration to mental health. LN acknowledged the importance of lived experience and spoke about her own experience of supporting her father who lived with dementia.

MM spoke about the work taking place across all of the RPB's, and urged CPG members to reach out and get involved.

Discussion on Dementia and Terminology

NH gave a presentation on Dementia and Terminology. NH introduced himself and the work which he does as chair of the 3 Nations Dementia Working Group, covering Wales, England and Scotland. Discussions at focus groups showed that people were uncomfortable with labelling.

Asked the question- does it make you feel comfortable when you or a loved one is described as 'having dementia'? The feedback suggested that the answer was 'no'.

Spoke about the background of the term, which dates back to the 13th century. Some of the questions asked included- Would you like to see the term dementia being used less, as well as what term would you like to see used instead of dementia? People felt that the term dementia has negative assumptions. Some people thought that the problem might not be with the word dementia itself, but with people's perception of dementia.

There was no consistency regarding what a new term could look like, however it was suggested that the letter 'a' could be used before the word 'dementia'. Education was a major recurring theme across the groups- greater education and awareness of what dementia means amongst the public.

AW agreed with NH, although stated that he also has difficulty in trying to find an alternative term.

CH noted the importance of the language used, and some of the issues which may cause stigma. There needs to be a national conversation.

Dementia and Sport

HO mentioned that Alzheimer's Society Cymru have met with the FAW to discuss the support that they are putting in place for current and former players. Mentioned that they have not had much response from WRU.

Asked whether Members would be open to inviting organisations such as WRU and FAW to a future meeting of the CPG on Dementia to discuss the work that they are doing on dementia.

HF mentioned that they would be happy to raise this with them on behalf of the CPG.

AW mentioned that boxing also has a big problem.

AOB

HW mentioned that Dementia Friends is a great tool for increasing awareness around dementia, and more could be done to promote this.

Date of Next Meeting?

January or February 2023