

## **CPG Meeting Notes – 13/07/22**

Attendees:

Rhys Ab Owen MS; Sion Jones; Huw Owen; Sue Phelps; Ceri Higgins; Andy Woodhead; Nigel Hullah; Versha Sood; Lilli Spires; William Davies; Ollie John; Karyn Davies; Rebecca Cicero; Melanie Sillett; Rosslyn Offord; Andrea Nicholas-Jones; Helen Cunliffe; James Ibell; Rebecca Hanmer; Helen Twidle

Apologies: Peredur Owen Griffiths MS; Llyr Gruffydd MS; Rhun Ap Iorwerth MS; Catrin Edwards, Catrin Hedd Jones; Lowri Williams, Benedict Hodge, Valerie Billingham; Michaela Morris; Claire Morgan.

### **Introductions**

RhAO welcomed everyone to the meeting and asked attendees to introduce themselves via the chat box.

### **Actions from previous meeting**

A letter was sent on behalf of the CPG to the Deputy Minister for Mental Health and Wellbeing, Lynne Neagle MS and we received a response (both shared with members of the group).

A letter was sent by the Chair of the CPG to the Chair of the expert group on the National Care Service. Response will be shared with Members once it is received.

### **Let's Talk Dementia PODS : Getting It Right': Update from Lleisiau Dementia**

AW, CH and NH gave a presentation on behalf of Lleisiau Dementia about the Let's Talk Dementia PODS project.

AW stated that the recent co-operation and openness in recent PODS meetings have been great. More people are willing to participate from within healthcare settings.

NH spoke about the meaning behind PODS- Positive Outcomes in Dementia Spaces. Important for Wales to have an independent voice for people affected by dementia in Wales. The PODS are safe spaces, and are open to staff at health boards, local authorities, third sector organisations, regional dementia boards and people with lived experience of living with dementia, and carers.

CH explained that the sessions start with an icebreaker, to tackle the grey matter around communication- only 7-8% of communication is words. Example of icebreaker- 'What does identity mean to you?'. Some of the titles are connected to the Dementia Standards, and are representative of what people affected by dementia and healthcare professionals said at the beginning of coproducing the standards. CH emphasized that the PODS support coproduction, and thanked

The theme for the PODS are:-

1. Coproduction and Engagement
2. Communication
3. Early Diagnosis
4. Care after Diagnosis
5. Care in Hospital

NH stated that if anyone has any questions or would be interested in joining future PODS, contact Tina Oakes at Improvement Cymru.

Chair thanked AW, CH and NH for their presentation, and praised the project and the importance of getting people talking to each other.

### **Update from Alzheimer's Society Cymru on Dementia Standards and Data**

HO mentioned that an announcement is expected with the findings of the expert group on exploring a National Care Service for Wales. HO also praised the work of the PODS having attended on the previous day, encouraging people to do the same.

HO mentioned that September's Senedd debate on dementia included a reference to creating a dementia data observatory. This work has progressed, and we are on the right track to having one in all but name. The Standards have a workstream focussing on measurements, and some of the questions asked to Dementia Leads in healthboards include; what the barriers are preventing them from collecting, sharing and having access to data is. The ability to talk to each other is really, really useful, particularly where data is involved. The group is in the process of establishing what data should be collected, what those barriers are, and then we can break those down.

HO mentioned that Welsh Government have agreed to work with the Welsh Ambulance Service Trust to investigate their data collection and sharing project which is being undertaken by WAST to improve the speed of data collection, the accuracy of data collection and the speed of that transfer to a hospital setting. WG have also agreed to work with the DOIIG to look at monitoring and reporting around the new Regional Integration fund projects that have been delivered by regional partnership boards, essentially across the pandemic. WG have also agreed to look at access to different data banks, and work with Alzheimer's Society Cymru to establish what data it currently holds.

RO mentioned that there's work going on with PHW to develop outcome measures specifically around dementia, because the mental health measures don't really fit very well. Asked whether this work is connected? HO mentioned that it definitely should be, and will pick up on this outside of meeting, and for RO to be put in touch with C&V 5B lead.

### **Update from Alzheimer's Society Cymru on findings of Senedd's Health and Social Care Committee's Report on Hospital Discharge**

HO mentioned that we have seen strong positive response to what the CPG put in the report on Hospital Care in Wales since its launch in terms of solutions and recommendations. The report has gone to the DOIIG and to Welsh government with promises to work with us and with the group to deliver on some of the solutions that are in there.

The report has also gone to the Senedd's Health and Social Care Committee as part of Alzheimer's Society Cymru's evidence into the impact of hospital discharge and its impact on patient flow through hospitals. ASC gave evidence alongside an unpaid carer, who shared her heartbreaking experience of the discharge process.

The report features an entire section dedicated to people affected by dementia, and our evidence and the CPG's report is referenced heavily.

There are 3 Key Recommendations from the Report:-

1. the Welsh Government should mandate further dementia training for NHS staff who may come into contact with people living with dementia.
2. Welsh Government should work with health boards to set-up pilot schemes to trial set discharge slots for people with dementia, and report the findings to the Health and Social Care Committee.
3. Welsh Government should explore options for opening up access to hospital wards for families, carers and, where appropriate, care home staff to help with day-to-day tasks and provide reports to the Health and Social Care committee.

HO mentioned that the Committee were particularly struck with some evidence that the CPG found when speaking to care homes. We will circulate the recording of the committee session with the minutes. We're awaiting the Welsh Government's response to the recommendations in that report, but we're incredibly hopeful based on the strength of evidence that went to the committee, that we will get a positive response.

CH mentioned the importance of ensuring that these reports and their findings are put into action. Important for people with lived experience who share their stories and experiences to feel that their contributions are valued and lead to timely action.

RC emphasized the importance of ensuring that the right type of training is undertaken. It's not about understanding necessarily what different types of dementia are, it should be about how you effectively and support and understand and a person living with dementia.

SP mentioned the importance of ensuring that the report leads to action, and stated that better integration between health and rebalancing between health and social care is going to be crucial.

### **Date of Next Meeting?**

After Recess (Late September/October). RHaO mentioned that the Deputy Minister has accepted the group's invitation to attend, and provide an update on dementia within WG.

### **AOB**

CH highlighted the Hear our Voices Project in CTM. Praised the project and its excellent coproduction, and that it should be rolled out across Wales.

AW flagged a group which he is involved with looking at the use of antipsychotic drugs on people with dementia.