

# Cross Party Group on Dementia

Minutes: October 2019



Tuesday 8 October 2019, 12:00pm-1.30pm

Conference Rooms 1 & 2, Y Pierhead

Chair: Lynne Neagle AM

Present: Lynne Neagle AM (Chair)

Huw Owen, Sue Phelps, Meryl Randell-Jones, George Parish-Wallace (Alzheimer's Society Cymru), Nigel Hullah (3 Nations Dementia Learning Group), Gwyneth Sweatman, Monica Reardon (Marie Curie), Dr Tracey Bedford, Hattie Hendra (Opinion Research Services), Karyn Davies (University of South Wales), Laurence Edwards (Swansea University), Louis Mertens (RCPSYCH), Dr Rosslyn Offord (British Psychological Society), Irina Erchovaia (Cardiff University), Charlotte Knight, Eleri Cabbage (Welsh Assembly), Dr Natalie Elliot (NCSLT) Linda Willis, Ceri Higgins.

**Lynne Neagle AM** welcomed everyone to the meeting and asked everybody present to introduce themselves, stating their name and organisation.

**Dr Tracey Bedford (TB)** then presented to the CPG on the Evaluation of the Implementation of the Dementia Action Plan for Wales on behalf of Opinion Research Services (ORS).

TB briefly introduced ORS as an organisation, explaining that they mainly work for the public sector, including on policy areas such as housing health, local & national Government and emergency services. The overall structure of ORS was then described, with ORS now working as an independent research company (formerly of Swansea University).

TB explained that the overall aim of the evaluation currently being undertaken is to provide the Welsh Government with timely and robust evidence about the aims, implementation and contribution of the Dementia Action Plan (DAP) from the perspective of key stakeholders across dementia services, including in health and social care, people living with and affected by dementia and carers. This will be achieved by:

- Assessing the contribution that the DAP has made to improve and extend the lives of those living with dementia, thereby enabling them to live in their own communities;
- Exploring how best practice is achieved;
- Identifying key gaps in existing data and aiming to strengthen the contribution assessment;
- Capture new data from individuals with dementia, their families and carer to assess the role and impact of the TAI mode, including the work of the Dementia Support Worker

The key objective of the assessment being undertaken by ORS is to provide Welsh Government with timely and robust evidence on the success of the DAP and its impact on the ground.

As part of the research process, an Initial Assessment Phase has been undertaken, consisting of ethical approval, a literature review and scoping interviews with DOIIG members.

In addition, there has been an assessment of known current performance conducted in order to inform areas where the DAP has succeeded or is lacking in practice for people living with and affected by dementia.

**Hattie Hendra (HH)** mentioned that, in terms of the literature review, there is currently very little relevant literature available. As a result, ORS are particularly eager to hear from organisations and people living with and affected by dementia in order to inform their findings from the research process.

**TB** then explained the research process in more depth.

Firstly, face-to-face interviews or paired qualitative depth interviews will be carried out with families, carers and discussion groups. ORS will also undertake a small number of longitudinal 'case study' interviews. In addition, there is the possibility of an optional quantitative survey, although it was emphasised that this is still being agreed upon.

Further, there will be engagement with key stakeholders, including professionals and other frontline staff, including deliberative events and workshops with the DOIIG and voluntary sector organisations, focus groups and those frontline staff working within dementia care.

The interviews with the stakeholder and other groups in phase one of the assessment will then be re-assessed in 2021 to evaluate what has changed, what is working and what needs to be reformed in order to improve the lives of people living with and affected by dementia on the ground.

An in-depth report will then be published in both English and Welsh languages.

Overall, the key aim of the report will be to assess if the DAP is working and achieving success. It will also identify those areas or regions that provide good quality care, and compare them with areas that do not, thereby offering a point of comparison for future policymaking and implementation.

It was also emphasised that research is only as good as the quality of data collected and so ORS are very keen to obtain accurate, robust and clear data to in turn provide the most accurate picture of conditions on the ground. This will make the report more effective and impactful.

Questions were then taken from ORS representatives on the presentation.

**Cerri Higgins (CH)** said that it would be very useful if those who were involved in the original consultation process that informed the DAP were included in the assessment being undertaken by ORS.

**Nigel Hullah (NH)** said that there were 12 meetings organised by Alzheimer's Society (with DEEP Network as equal partners) that led to a clear set of recommendations for the Welsh Government when formulating the DAP.

As such, the key asks from the meetings were that respite care is provided for carers and that care is orientated around the individual, as opposed to the individual having to adopt to the model of care provided.

**Sue Phelps (SP)** said that people affected by dementia absolutely need to be included in the ORS research and assessment of the DAP.

Over 1,000 people engaged with the initial consultation process and it is important that the existing network is fully engaged in evaluating the success of the DAP, as well as new networks.

The rights of people living with dementia is also equally important, as are the rights of those affected by throughout the entire journey of dementia, from initial diagnosis to end-of-life care.

**TB** said that ORS genuinely care about the cause of the evaluation and assessment of the DAP.

**SP** added that this is a unique opportunity for Wales to impress and set a precedent on a European level.

**Linda Willis (LW)** said that carers should be included in the plan.

**Huw Owen (HO)** then presented on the CPG's Inquiry into Hospital Care for people with dementia.

He explained that the inquiry was initially launched in the form of a narrative based survey in October 2018, aimed at gathering stories and shaping thought processes around recommendations.

Then, in the summer of 2018, a quantitative survey was launched which aims to provide statistical weight to the proposed recommendations.

In addition, as part of Phase One, roundtable events were held with regional Assembly Members and in constituencies. Locations included Pontypool, Wrexham, Newport and Llangefni.

There were also a series of organisational roundtables that commenced in 2019. Attendees for the organisational roundtables included representatives from MacMillan, the Royal College of Nursing and student nurses from the University of South Wales.

There has been a total of 11 responses from members of the public and written responses from a variety of organisations, including Health Boards, Charities and Professional Bodies.

Finally, there was also an oral evidence session with Age Cymru, The Royal College of Nursing and Dr Katie Featherstone forming the panel.

The inquiry has also taken the form of regional hospital roadshow events across Wales which are being conducted throughout October 2019.

**HO** then showed the initial findings of the inquiry to those present, which broadly demonstrated that most people surveyed feel that dementia care in hospital across Wales is poor.

In particular, 24.5 per cent of those surveyed think that A&E care for people with dementia is 'Very Poor' whilst just 8 per cent of those surveyed feel that medical staff have an 'Excellent' knowledge and understanding of dementia.

In terms of next steps, the hospital roadshow events will be concluded by the end of October. The deadline for the completion of the survey is then 31 December. A report will subsequently be drafted by February 2020 with the launch of the report by the CPG to Welsh Government taking place in the spring of 2020.

By way of recommendations, the report will likely focus on:

- Involving carers in all areas of dementia decision-making
- A&E sign-posting and cooperation
- Enabling staff to take positive risks
- Having a dedicated dementia specialist in each hospital unit
- Full use of 'This is me' forms upon admission
- Having a system of identifying people with dementia
- Use of volunteer services

**LN** then asked if there were any questions or comments for **HO** on the presentation.

**Dr Dr Rosslyn Offord (RO)** said that she hoped the results would be published in a way that was sensitive to the difficulties staff were facing, so that they could be heard and acted on in a constructive way, especially given the difficulties we face with recruitment and retention. In addition, **RO** said that staff are under pressure because of systemic issues.

**HO** said that task-orientated care is an issue in hospitals presently, as opposed to time-orientated care. As such, the CPG's report will look at suggesting changes to the care system in order to encourage better care that is more suited to the individual, as opposed to time restraints.

In addition, **HO** said that the recommendations of the report will be presented as potential solutions to measure progress against.

**LN** said that the presentation of the report itself would have an impact on the likely overall impact of the report upon the Welsh Government. As such, **LN** explained that CPG reports carry less influence than Committee reports. The Government are not obliged to respond to a CPG report in the same way as a Committee report. Committee reports must be responded to, according to Standing Orders, within six weeks of publication. However, this is not the case for CPG reports.

**Irina Erchovaia (IE)** emphasised the importance of comparing dementia patients with other patients across the NHS. All NHS issues cannot be solved through the same set of recommendations.

**CH** asked how the CPG will learn from those people who do not access surveys, GP services and other health services and are isolated.

CH then asked if the CPG could collect data in other areas and settings, such as at supermarkets. In settings outside of hospitals, people are generally more relaxed and honest in their responses to data surveys. CH emphasised the importance of including isolated people in the data gathering process.

**MRJ** said that outpatient care is different to in-patient care. However, there is a level of honesty in the roadshow events that has been encouraging to see. There have been positive experiences in the data gathering process.

**MRJ** said that there are different levels and standards of care in the same local areas. Therefore, ensuring consistency of care and continuity for people affected by or living with dementia is of vital importance.

**Monica Reardon (MR)** asked about under-represented groups and emphasised the importance of gathering data from such minority groups, especially in the ORS assessment of the DAP.

**LN** said that people working in the medical profession and in hospitals tend to give a more positive set of results for quality of care in hospitals for people with dementia than patients themselves. This is an issue as this could potentially be mis-represented in the data and give the impression in the results that the quality of care is better than it is in reality.

**HO** then explained the different categories of the person description in the survey forms for the hospital inquiry.

**MRJ** said that, interestingly, some survey participants are filling in more than one survey. They are answering from a professional capacity as a medical professional and one from a personal perspective as a carer.

**LW** said that there are different diagnoses' in the medical profession, and that people living with dementia need an accurate diagnosis at the start of their dementia journey, as opposed to an inaccurate diagnosis, which complicates matters and medical procedure.

**SP** said that the areas around admission and discharge are key components of the survey and added that social care plays a huge part in this. SP then emphasised the importance of engaging with social care representatives in order to improve overall care for people living with dementia.

**HO** said that, by 2021 the CPG will be in a better position as the next Government will be in place. This will make it easier to make representations and recommendations to Welsh Government.

**LN** then thanked Alzheimer's Society for all of their work with the hospital inquiry.

A Dementia Learning & Development Update was then passed around attendees on behalf of the Dementia Learning & Development Group.

**AOB**

**Future meetings**

Tuesday 3 December 2019 - AGM (will need to elect/re-elect Chair and Secretary)

Tuesday 3 March 2020

Tuesday 19 May 2020

All 12 noon – 1.30pm in Y Pierhead