

# Focus on Dementia

## Post-diagnostic Support Leads Network Meeting

### Flash Report

12 June 2024

## **Thank you for joining the Focus on Dementia PDS Leads Network meeting**

We were delighted that 38 members of the group attended the virtual meeting using MS Teams, on Wednesday 12 June 2024.

Susan Banks, Co-Chair and PDS Lead Dundee Health and Social Care Partnership (HSCP), welcomed everyone. A summary of agenda topics is listed below with full information available on the slides [here](#).

### **Focus on Dementia update**

Michelle Miller, Portfolio Lead for Community Care and Dementia, Healthcare Improvement Scotland provided an update on Focus on Dementia.

The Focus on Dementia team welcomed Gillian Fergusson, Senior Improvement Advisor and Adeline Tan, Improvement Advisor. Gillian has worked with Healthcare Improvement Scotland's People Led Care team for several years and has a background in the third sector. Adeline is moving from SPSP Primary Care and will be starting on 17 June 2024.

This will allow the team to begin on Reducing Stress and Distress for People with Dementia in Inpatient Settings Improvement Programme. The team has developed a Quality Improvement Framework, assessment tool and guidance and will be testing the paperwork over the summer. Once learning from the testing has been incorporated, the improvement programme will start later in the year. A delivery group is being set up to provide advice and guidance.

The 1-year PDS Improvement Programme with Dundee HSCP, Edinburgh HSCP and NHS Lanarkshire ended in May 2024. An evaluation report is being developed to evidence what went well and whether anything could have been done differently. Learning will inform any future PDS Improvement Support provided. The report will be published in September 2024.

### **Scottish Government Dementia Policy update**

Gordon Dodds, Dementia Policy Manager, Scottish Government provided an update on key deliverables for the [dementia strategy](#).

- Anti-Stigma Campaign – some changes have been made to the language used in the advert and posters. The launch has been rescheduled to early September due to the unanticipated General Election news. Once the campaign is launched, PDS leads are asked to promote it in local areas.
- Brain Health Service Evaluation – the next meeting of the evaluation assurance group, chaired by Alastair Cook, Principal Medical Officer is on 13 June 2024.
- Data - the first meeting of the data delivery subgroup will take place on 17 June 2024, co-chaired by Martin Robertson, as a member of our Lived Experience Panel and Terry Quinn, Chair of the Scottish Dementia Research Consortium. This group is to progress deliverable 3 of the [delivery plan](#).

- Workforce – the first meeting of the short life working group is on 19 June 2024. The group is co-chaired by Fiona Maclean, Napier University and Alan Gall, National Dementia Lived Experience Panel. The purpose of this group is to progress deliverable 4 of the delivery plan.
- Resilient Communities Programme Board – The first meeting of the Board is on 12 June 2024. The group will be chaired by Angela Currie and Ron Coleman. The purpose of this group is to progress deliverable 6 of the delivery plan.

Gordon has also been working on progressing the request for PDS monitoring returns 2023-2024 and the proposed PDS independent evaluation. While there has been a good response from IJBs, there are still a few outstanding. The PDS leads were asked to contact Gordon with any queries.

The proposed independent evaluation of PDS policy and delivery, including the perspective of people living with dementia and care partners/unpaid carers and those living in care homes will be later in the year. The evaluation will provide evidence of the value and impact of PDS to date, helping inform future PDS policy, service planning and practice. Further information will be provided when available.

### **Public Health Scotland update**

Zeg Ashraf, Data Manager, Public Health Scotland provided an update on the latest data submissions and management reports as of 31 March 2024. If you are experiencing any issues with your PDS data, please [email](#) the team.

Zeg also advised PHS published the Dementia PDS annual report that sets out data for the year 2021-2022. You can find the report [here](#).

Dr Megan Cameron (FY2 doctor in Public Health) who is working with Dr Paul Nelson (CPHM NHS Lanarkshire/PHS and dementia PHAcT lead) attended to ask members for their help to gather an overview of how PDS services for dementia operate within different NHS boards and HSCPs across Scotland. A survey was circulated with a deadline of 21 June 2024. If you would like to discuss this further, please contact [Megan](#) directly.

### **Poll topic: Rare Dementia Support**

Jill Walton and colleagues from University College London presented on services available from Rare Dementia Support. The service offers holistic support in the community based on the person's specific dementia and their situation to offer the right help at the right time. This could be by offering one-to-one support and small or large group meetings.

The organisation is London based and they are trying to branch out within the UK. They currently facilitate two online support groups in Scotland and aim to create a series of regional network hubs to enhance support for people living with and caring for someone living with a rare dementia in the UK. Jill also shared information on a handbook and brochure

that will be circulated to the group. Members asked to contact the [team](#) for any further information.

### **Suggestions for future Spotlight sessions**

Susan explained the update on rarer dementia was the final suggestion from the previous poll on topics network members wanted to feature. Members were asked to put comments in the chat box, or to contact the Focus on Dementia team with any suggestions for future agenda items at [his.focusondementia@nhs.scot](mailto:his.focusondementia@nhs.scot).

### **Open forum – space to share developments and to pose queries to the group**

Susan asked the group to share any recent experiences or anything else they would like to share.

Della from NHS Lanarkshire asked members whether anyone else was using the PDS Quality Improvement Framework and Single Quality Question, and for any advice around consent when publishing data from the information gathered. Please contact Della or her team if you can help. Maureen Taggart advised the Alzheimer Scotland has been using the SQQ for a few years and would be happy to chat further.

### **Next steps**

The next meeting takes place on **Wednesday 11 September 2024, 10:00–12:00** on MS Teams.

Contact the Focus on Dementia [team](#) for any further support or information and with any future spotlight session suggestions.

All slides are available [here](#).