

Focus on Dementia

Post-diagnostic Support Leads Network Meeting

Flash Report

11 September 2024

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

We were delighted that 40 members of the group attended the virtual meeting using MS Teams, on Wednesday 11 September 2024.

Gillian Gibson, Chair and Nursing Officer, Mental Welfare Commission for Scotland, welcomed everyone. A summary of agenda topics is listed below with full information available on the slides [here](#).

Focus on Dementia update

Julie Miller, Improvement Advisor, Healthcare Improvement Scotland provided an update on Focus on Dementia.

The Focus on Dementia team will soon be back up to full resource when Stephen Lithgow starts as Senior Improvement Advisor in October 2024. Gillian Fergusson (Senior Improvement Advisor) and Adeline Tan (Improvement Advisor) from the team joined our meeting today to update on the Reducing Stress and Distress Improvement Programme.

Julie previously advised that FoD were supporting Edinburgh Health and Social Care Partnership to spread and co-ordinate NHS Lothian's practice of PDS link workers contributing to key information summaries in patients' general practice record. Generic documentation is now available on NHS Lothian's website that can be adopted locally by services. The documentation can be found [here](#).

Julie has been working on finalising an evaluation report, which will show the impact of our 1-year light touch quality improvement support approach for PDS teams. It will include impact stories from Dundee Health and Social Care Partnership, Edinburgh Health and Social Care Partnership and NHS Lanarkshire. The report will be available later this month on our [website](#).

Julie and the team will be working on the third edition of the PDS Quality Improvement Framework (QIF) and associated resources. This update will reflect the publication of the dementia SIGN guideline and include a section on young onset dementia. If you would like to volunteer to help with this review please contact the FoD team [here](#).

The team are also at a stage to consider what the next PDS improvement support offer should look like. A workshop is being held in November 2024 to help us shape this, however Julie asked the group to consider what QI support would be welcome and what method would appeal to members (a poll was circulated in the MS Teams chat). Responses will inform discussion at our workshop.

Julie then presented data collated by Dr Megan Cameron who conducted a survey at our last PDS leads network meeting regarding standing operating procedures (SOP) for PDS. Megan's PHS placement has ended so she asked that we share her findings and her thanks for those who responded. The survey responses fell in favour of continuing to explore the development of a national SOP. Dr Paul Nelson of PHS will take this forward. You can find Megan's data from [slide 8](#).

Julie also advised on some upcoming events:

- Alzheimer Scotland Annual Conference, EICC Edinburgh (20 September 2024).
- Medication reviews for older adults living with frailty webinar (3 October 2024, 1-2pm) – you can register [here](#).
- Scotland leads the way: pioneering brain health and dementia prevention webinar (9 October 2024, 10am-12noon) – you can register [here](#).
- Ageing and Frailty Standards are due to be published late November 2024.

Gillian Fergusson, Senior Improvement Advisor, Healthcare Improvement Scotland provided an update on the Reducing Stress and Distress Improvement Programme

We will work with a number of teams across hospitals and care home settings to support improvement in the prevention and management of stress and distress for people living with dementia. This programme is a collaboration between Healthcare Improvement Scotland, the Care Inspectorate and NHS Education for Scotland and will work with a range of health and social care stakeholders including people with lived experience of dementia.

We have tested a new Reducing Stress and Distress self-evaluation tool with teams from NHSScotland and care homes. Feedback is being incorporated ahead of applications being launched at Alzheimer Scotland's conference on 20 September 2024. The improvement programme will then launch on 4 December 2024 and we will run four cohorts throughout 2025.

Scottish Government Dementia Policy update

The group welcomed Laura Ferguson, Senior Policy Advisor, Scottish Government to provide an update on key deliverables for the [dementia strategy](#). Laura has joined the network as Gordon Dodds has moved to a different team.

- **PDS evaluation** – work is progressing with Scottish Government to support the independent evaluation. An assurance evaluation group will also be set up with members from the strategy delivery group and will have a role of shaping the evaluation. Laura could not advise on set timescales of this work as yet, however she confirmed it is going ahead with the intention of starting early 2025.
- A **strategy and delivery group meeting** took place 10 September 2024 where updates from the 2-year delivery plan were shared from members of the sub-groups.
- The **workforce short life working group** will map out what the current resources and tools are, who is accessing the development tools, who benefits from it and how is it being delivered to establish the need for further development.
- The **data delivery group** are considering challenges around data. Jill Carson sits on the data sub-group and advised that the PHS proposal is around a national dementia register, created nationally for stakeholders to apply to get access to relevant information - similar to work carried out in [Midlothian HSCP](#). The group will consider aggregating data from a

number of resources, social work, hospital returns, outpatient return. Bringing all these sources of data together to identify anyone with a diagnosis of dementia.

Public Health Scotland - PDS data update

Amy Hynd, Data Manager, Public Health Scotland provided an update on the latest data submissions and management reports as of 30 June 2024. If you are experiencing any issues with your PDS data, please [email](#) the team.

Young Onset Dementia update

Jill Carson, Policy Consultant, Alzheimer Scotland updated on her work around young onset dementia and her previous paper circulated to the group.

The report set out best practice and some recommendations for improvements. Having considered the recommendations, creating something like FoD's PDS QIF is desirable – a more supportive document setting out areas for services to consider when making improvements. Now that the PDS QIF is being reviewed, it's a good place to start by incorporating more detail around young onset dementia and PDS. Other frameworks may need to be created in the future as we know there are challenges for people before diagnosis and after PDS.

Spotlight session – Speech and Language Therapy and PDS

Lisa Fox, Specialist Speech and Language Therapist (SLT), Enhanced Community Dementia Service, Argyll and Bute presented to the group about her role in PDS.

Lisa's slides include a couple of videos that she did not share on the day but can be found from slide 32 of the presentation [here](#). Lisa also asked us to share her blog Let's talk about dementia, which can be found [here](#).

Susan Banks and Jenny Keir then shared their work and progress on forging better connections between the Dundee PDS Team and Jenny who is an SLT in Dundee HSCP.

The network members were reminded to get in touch with FoD with any other suggestions for future agenda items at his.focusondementia@nhs.scot.

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

Susan reminded the group this is the point of the meeting where network members are asked to share any recent experiences or ask any questions from the group.

Natalie Minick, Senior Community Mental Health Nurse, NHS Tayside, shared her improvement project on the creation of a QR code to gather feedback from people with dementia and their families on their PDS. This method of asking people the Single Quality Question for PDS and capturing feedback has seen an increase in feedback received and is being rolled out wider in NHS Fife.

Next steps

The next meeting takes place on **Wednesday 11 December 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](#).