

## Focus on Dementia

# Post-diagnostic Support Leads Network Meeting

Meeting report

11 December 2024

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

We were delighted that 37 members of the group attended the virtual meeting using MS Teams, on Wednesday 11 December 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 team are working on the third refresh of the PDS Quality Improvement Framework to reflect the SIGN Dementia guidelines. This is due to be published in March 2025 and will include a new section on young onset dementia. Once this is complete, we will work with Alzheimer Scotland to refresh the [Making the most of your post-diagnostic support](#) companion document.

Julie also reflected on the previous work including:

- Diagnosis and post-diagnostic support in primary care ([Diagnosis and Post-Diagnostic Support in Primary Care - Diagnosis and Post-Diagnostic Support in Primary Care](#))
- The work with Inverclyde Health and Social Care Partnership that supported improvements and redesign of community based services to improve the experience, safety and co-ordination of care for people with dementia from diagnosis to end of life care ([Inverclyde Care Co-ordination - Inverclyde Care Co-ordination](#)).
- Midlothian Health and Social Care Partnership were seen as an exemplar from the previous 8 Pillars evaluation. We wanted to understand what were their critical success factors and did it actually lead to positive outcomes, so we led an appreciate inquiry and data analysis which concluded ([Midlothian Care Co-ordination | Focus on Dementia | ihub - Midlothian Care Co-ordination](#))

**Stephen Lithgow, Senior Improvement Advisor, Healthcare Improvement Scotland** provided an update on the next phase of PDS and what we consider the high impact changes to focus on:

- Quality – a consistent approach to supporting quality by embedding the use of the Quality Improvement Framework (QIF) in PDS services.
- Personal plan – everyone receiving PDS should be working towards having a personal plan as a key part of their support, including early conversations about issues such as Power of Attorney.
- Multidisciplinary care co-ordination -for those requiring more co-ordinated support.

We are developing what our improvement offer will look like in 2025 and will communicate the offer early in the new year

Stephen also updated on the Reducing Stress and Distress Improvement Programme. Applications were open from 20 September-1 November 2024 and 118 applications were received (86 care homes, 32 hospital teams). We are in the process of holding an initial meeting with all 53 successful teams to

introduce them to their coaches and the 12-week improvement cycle. The programme will be delivered with four cohorts throughout 2025. They will then be added to a collaborative to share and learn from each other. A self-evaluation tool and change package will be published before the programme starts on 13 January 2025.

**James Battye, Senior Improvement Advisor, Healthcare Improvement Scotland** updated on Focus on Frailty. Focus of Frailty's aim is that people living with, or at risk of frailty have improved experience of, and access to person centred, co-ordinated health and social care. This will be achieved by early identification and assessment of frailty, people living with frailty, carers and family members access person-centred health and social care services, and leadership and culture to support integrated working.

The team continue to share learning through its national frailty learning system with over 1,975 members on an MS Teams channel. Contact the team if you would like to join the network ([his.focusonfrailty@nhs.scot](mailto:his.focusonfrailty@nhs.scot)). You can find out more information on Focus on Frailty [here](#).

The [Ageing and frailty standards](#) were published in November 2025 and apply to all settings. They act as a benchmark for progress towards nationally consistent integrated frailty services

## Scottish Government Dementia Policy update

**Laura Ferguson, Senior Policy Advisor, Scottish Government** to provide an update on key deliverables for the [dementia strategy](#).

One of the key policy aims in Scotland's new dementia strategy is improving on the uptake and delivery of PDS. An independent evaluation of Scotland's PDS policy and delivery will be carried out over 2025-2026. An Evaluation Assurance Group has been set up with representation from national and local partners, as well as members of the Lived Experience Panel. The group provided feedback on the evaluations, aims, objectives and key questions.

## Dementia Strategy Delivery Plan Update

- Re-think Dementia Campaign – following the campaign's run, the next stage is evaluation to measure its success.
- Workforce Short-life Working Group – NHS Education for Scotland (NES) and Scottish Social Services Council have committed to understanding the wider 'dementia workforce' through commissioning work to gather the knowledge of the group and the voices of lived experience.
- Bain Health Service – Blake Stevenson, have provided an interim report on an independent evaluation to gauge the impact of the Brain Health Service in Aberdeen.
- Data – Public Health Scotland (PHS) presented a proposal to the data subgroup on a dementia index that would aim to use anonymous points of interaction people have with the health and social care system to record people who are living with dementia.

## Spotlight session: Information and training for carers - opportunities to connect with Age Scotland

**Rachel Davison, Dementia Training Officer – Carers’ Rights Lead, Age Scotland** updated the group on support available for carers. Funding was awarded from April 2024 for 2 years. Workshops are offered in partnership with local carers centres, carer support groups, meeting centres and other voluntary organisations – both online and face to face. The [Dementia training carer engagement report](#) was published in November 2024.

Dementia Training at Age Scotland:	Workshops for carers:
Dementia awareness workshops	Hospital admission and discharge
Dementia friend community workshops	Dementia awareness
Dementia inclusion workshops	Dementia and communication
Dementia workshops for workplaces	Introduction to the Carers (Scotland) Act
Workshops for unpaid carers	Residential care costs
	Dementia and the home environment
	Dementia – mood and wellbeing
	New to caring role (in development)

Workshops run regularly and some depend on the demand. There is a rolling programme available through the website [www.age.scot/dementia](http://www.age.scot/dementia). If you would like any further information email [dementiatraining@agescotland.org.uk](mailto:dementiatraining@agescotland.org.uk).

## Public Health Scotland update

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

Zeg also advised that a short-life working group has been set up to help consider what analysis should be included on the data collected to meet key deliverables. The group includes representation from Scottish Government, Healthcare Improvement Scotland, NHS boards, health and social care partnerships and people with lived experience. The data collected by PHS will consider demographic and qualitative detail. A draft report on this data will be produced in March 2025, with a view to publishing findings in June 2025. Zeg will feedback to the PDS leads network.

## Spotlight session: Confident Conversations training offer

**Jacqueline Kerr, Network Manager and Dr Emma Law, Manager, Neuroprogressive and Dementia Network, NHSScotland** updated the group on their joint work with Alzheimer Scotland to provide training for all staff about research conversations.

A toolkit has been developed following a 2-year journey. This will allow staff to continue to have these conversations. The toolkit signposts staff to available resources to support these conversations. You can find the toolkit and also the link to the presentation slides [here](#).

If you are interested in hearing more about the sessions or booking a session, contact [tay.ndntayside@nhs.scot](mailto:tay.ndntayside@nhs.scot). You can also contact them for access to any of the resources such as permission to contact forms, posters or leaflets.

## Open forum

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.

Julie had a late request from NES' learning disabilities team who developed two modules around dementia and people with learning disabilities, which is mapped to the promoting excellence framework. NES are hosting a session on Friday 13 December 2024 at 1pm, which we know is short notice. Julie will feedback that more notice in future would be helpful

## Next steps

The next meeting takes place on **Wednesday 12 March 2025, 10:00–12:00** on MS Teams and will focus on waiting lists. Get in touch if any good examples or suggestions for future spotlight. Contact the Focus on Dementia [team](#) for any further support or information.

All slides are available [here](#).

We would like to thank you all for the great work you have continued to do to support people living with dementia and their carers. We wish you all the very best for the festive season and look forward to working together in 2025.

