

Focus on Dementia

Post-diagnostic Support Leads Meeting

Flash Report

13 March 2024

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

We were delighted that 36 members of the group attended the virtual meeting using MS Teams, on 13 March 2024.

Gillian Gibson, Chair and Nursing Officer, Mental Welfare Commission for Scotland, welcomed everyone. A brief summary of agenda topics are 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.

There have been a few changes in the Focus on Dementia team recently; Lynn Flannigan and Marie Innes, both Senior Improvement Advisors have moved on. This means the team will have reduced capacity for a while, however we will continue to provide light touch support to the PDS improvement support teams. This will not impact the PDS Leads Network.

We are unclear about commissions in the year ahead. The Scottish Government policy team are working with the National Delivery Group to inform next steps around the delivery plan and will provide further updates at future PDS Leads Network meetings.

Link Worker input into Key Information Summaries

Julia Mackenzie, PDS Quality Lead, Alzheimer Scotland, provided an update on work in Edinburgh Health and Social Care Partnership where PDS Link Workers input key information about the people they are supporting into key information summaries (KIS) in GP patient records. The KIS allows clinical information from the GP electronic record to be shared across different parts of NHSScotland.

Having dementia Link Workers input to KIS was identified as one of the benefits from the dementia and primary care testing work. Edinburgh City Link Workers now routinely feed key personal plan information into KIS. Julia, and the Long Term Conditions Programme team, are keen to inspire other areas to build the foundations for this to happen more widely.

Focus on Dementia are working with Julia's team to share their learning and hope to host a generic PDS practitioner KIS bundle and guidance on our webpages. The resources will be shared when available.

Scottish Government Dementia Policy update

Gordon Dodds, Dementia Policy Manager, Scottish Government provided an update on the newly published [2-year delivery plan](#). This is the first in a rolling programme to deliver the 10-year [dementia strategy](#).

The delivery plan sets out the agreed priorities and how they will be monitored and measured. It sets out some initial key deliverables.

- A public facing anti-stigma campaign, co-produced with the Lived Experience Panel.
- Understand and add to the data we collect and publish on peoples' experiences of dementia care and support.
- Work with our diverse workforce that engages people living with dementia and their care partners, to understand how we can support them to enhance the support they provide.
- An independent evaluation of Scotland's world leading PDS policy and delivery.
- Commission an independent evaluation to assess the impact of our innovative Brain Health Service in Aberdeen.
- Establish a collaborative Resilient Communities Programme Board to drive investment to support sustainable dementia inclusive/friendly communities.
- Establish a cross-government, cross-sector steering group to help us understand the Scottish Government's role in the dementia identification, diagnosis, and treatment agenda, including the trialling of novel treatments that can slow the progression of some dementias.

Next steps include, publish impact assessments for our strategy, agree delivery monitoring and measurement framework with governance group, establish focused delivery groups, explore working with a local area(s) on 'the how' of delivering in a specific place and quarterly reporting to governance on progress against agreed priorities.

Public Health Scotland update

Amy Hynd and Zeg Ashraf, Data Managers, Public Health Scotland provided an update on the latest data submissions and management reports as of 31 December 2023.

Ongoing work includes estimates of incidence of dementia – to be developed by PHS Information Consultancy team. Estimates have been produced and are being evaluated. Annual publication of PDS data is delayed to May 2024. Public Health Scotland are working with Scottish Government on their role in helping deliver the objectives outlined in the Dementia Strategy initial 2-year delivery plan.

If you are experiencing any issues with your PDS data, please [email](#) the PDS Dementia team at Public Health Scotland and they will do what they can to help.

Poll topic: Housing and Dementia

Ashley Campbell, Policy and Practice Manager, Chartered Institute of Housing provided an update on housing, why it is so important to people living with dementia, and the importance of speaking with people early in their journey about their housing situation.

Two thirds of people with dementia live in mainstream housing and there is a national commitment to help people stay at home.

The [Housing and Dementia Framework](#) (2019) was designed to help organisations support people to live well with dementia. It sets out how housing organisations can support people living with dementia and their carers.

Ashley reflected on the Dementia Strategy, how housing is much better reflected throughout the document and how the action plan will be key to translating good intentions into better outcomes for people. Ashley also highlighted the need for joined up working across departments.

Young Onset Dementia Survey – summary report

Jill Carson, Consultant, Public Policy, Alzheimer Scotland, presented a report produced by the Young Onset Dementia Short Life Working Group.

Following discussion at a PDS leads meeting in 2021, it was agreed to establish a short life working group, chaired by Alzheimer Scotland, to explore service delivery for people with young onset dementia in Scotland, and to identify ‘best practice’ with the aim of improving access to appropriate services for people under the age of 65 who are living with dementia.

Key messages:

- We do not have (accurate) numbers of people with young onset dementia in Scotland - either for diagnosis, or for those being supported by services.
- There is significant variability (postcode lottery) from beginning to end: pre-diagnostic support, access to diagnosis, wait for scanning, time to diagnosis, availability of PDS.
- Variation can be within board but also within Health and Social Care Partnerships.
- There are multiple pathways to diagnosis in some areas.

The SLWG will produce a paper with recommendations for future services.

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

Julia Mackenzie highlighted that Edinburgh Health and Social Care Partnership have funded two additional Link Workers to work with people on the long waiting list for diagnosis. When someone is referred, a letter is issued to tell them about the wait and to encourage them to get in touch with a Link Worker for any additional support, or to access group sessions. This process has had a great response so far with 26 people attending the first group.

Natalie Minick shared through MS Teams chat a recent development in central Fife. Natalie has been working on a PDS project to gain feedback from patients and families for quality improvement purposes. Feedback was requested at 6 months, as well as at the end of PDS to be able to identify and work on any identified issues before PDS comes to an end. There is now a QR code to allow for easy access to the feedback form, which is working well. There has been a great response and, following testing, this is now being rolled out in NHS Fife.

Next steps, invite/suggestions for future Spotlight sessions

Susan Banks, PDS Leads Vice Chair, PDS Lead, Dundee advised that the Focus on Dementia team want to review the membership of this group. PDS leads are asked to consider if your service has the right representation in the group. Let the team know through the mailbox.

As always, consider if you have anything you would like to shine a spotlight on at future sessions and let us know.

The next meeting is on **Wednesday 12 June 2024, 10:00–12:00** on MS Teams.

All slides are available [here](#).