

The benefits to being part of a Dementia Post-Diagnostic Support Improvement Programme

Executive summary

Background and aim

Post-diagnostic support (PDS) is a service that people with dementia in Scotland are entitled to following their diagnosis. This support is delivered by a PDS worker, often called a dementia link worker, who is allocated to the person for at least one year. PDS for people newly diagnosed with dementia in Scotland has been a national commitment in the Dementia Strategy for Scotland since 2013.¹ These five areas were identified by Alzheimer Scotland in 2011 and are known as the 5 Pillar Model of Post-Diagnostic Support²:

- understand their illness and manage their symptoms
- stay connected to their community
- meet others who are coping with the same sort of challenges
- plan for future decision-making, and
- plan for future care by helping to develop a personal plan which captures what matters most to the person.

Provision of PDS is complex throughout Scotland with varying models of service delivery. PDS practitioners are responsible for the delivery of PDS across all health and social care partnerships. The majority are attached to community mental health teams, some with in-house NHS and health and social care partnership staff delivering and others with commissioned PDS from third sector staff, mainly from Alzheimer Scotland.

¹ <https://www.gov.scot/publications/new-dementia-strategy-scotland-everyones-story/>

² <https://www.alzscot.org/our-work/campaigning-for-change/current-campaigns/5-pillar-model-of-post-diagnostic-support>

Public Health Scotland data suggests not enough people newly diagnosed with dementia receive the support they are entitled to and people with lived experience tell us that the quality varies throughout the country. Without continuity and co-ordination of care and support, people with dementia, carers and families can experience poorly integrated care from multiple providers. Poor care experience, avoidable hospital admission and delayed discharge are often the result alongside unnecessary duplication of effort and work by care providers.

Within this context, Healthcare Improvement Scotland's Focus on Dementia team designed and delivered a 1-year PDS Improvement Programme to run from June 2023 to May 2024.

Through an application process, we received 14 applications and selected 3 PDS teams from the following areas:

- Dundee Health and Social Care Partnership
- Edinburgh Health and Social Care Partnership, and
- NHS Lanarkshire.

The purpose was to support the PDS teams to make improvements in line with the newly published Scottish Intercollegiate Guidelines Network (SIGN) Dementia Guideline³ which includes 20 specific recommendations for PDS under this key recommendation:

Post-diagnostic support should incorporate continuity of care, including a 'one-stop' service or single point of contact, a single professional or case manager. This should be a healthcare and social care professional with appropriate skills, knowledge and expertise in dementia (see the Promoting Excellence Framework⁴), working with the GP, to ensure a tailored support package is delivered in a timely manner.

Aims of the PDS teams

Each team decided to make improvements to different areas.

Dundee Health and Social Care Partnership focused on improving care co-ordination, creating diversity champions and establishing connections with speech and language therapy and primary care.

Edinburgh Health and Social Care Partnership aimed to improve access to PDS over the life of a 5-year commission and beyond with an external PDS provider. The delivery team wanted to lay the foundations to achieve these specific priorities: support through diagnosis and referral; recording and information sharing; equality and diversity, and transitions at the end of PDS.

³ <https://www.sign.ac.uk/our-guidelines/assessment-diagnosis-care-and-support-for-people-with-dementia-and-their-carers/>

⁴ <https://www.gov.scot/publications/promoting-excellence-framework-health-social-services-staff-working-people-dementia-families-carers/>

Lanarkshire Health and Social Care Partnership focused on establishing and testing a new pan-Lanarkshire PDS service. The team wanted to apply QI tools and resources throughout to give structure to the work and capture progress and impact to secure the future of the service.

The difference the improvement support made

The 3 teams were fully engaged throughout the programme and all embarked on making improvements to PDS and care co-ordination in their areas. Each site produced an impact story to capture examples of where the improvement support and subsequent activities had made a difference. Here are some examples of what was achieved:

Dundee Health and Social Care Partnership

- Developed closer working relationships with primary care
- Created an equality and diversity champion
- Delivered awareness sessions for the Dundee city workforce
- Forged strong connections with allied health professional (AHP) services
- Designed a new project to provide support to people once PDS is completed
- Created an information pack on technology for people living with dementia and their carers

Read the [Dundee PDS Team impact story](#).

Edinburgh Health and Social Care Partnership

- Carried out analysis of where people were being diagnosed and where referrals were coming from to ensure there are appropriate referral pathways
- Developed an Equality Impact Assessment (EQIA) to focus efforts
- Improved TRAK access for PDS link workers to support better recording and info sharing
- Created pre-diagnosis support for people on the waiting list for diagnosis.

Read the [Edinburgh Health and Social Care Partnership impact story](#).

NHS Lanarkshire

- Established a new PDS service – an extensive undertaking for NHS Lanarkshire’s project lead and team
- Embraced and applied QI tools and resources throughout
- Made quality improvement business as usual for the team

Read the [Lanarkshire PDS Team impact story](#).

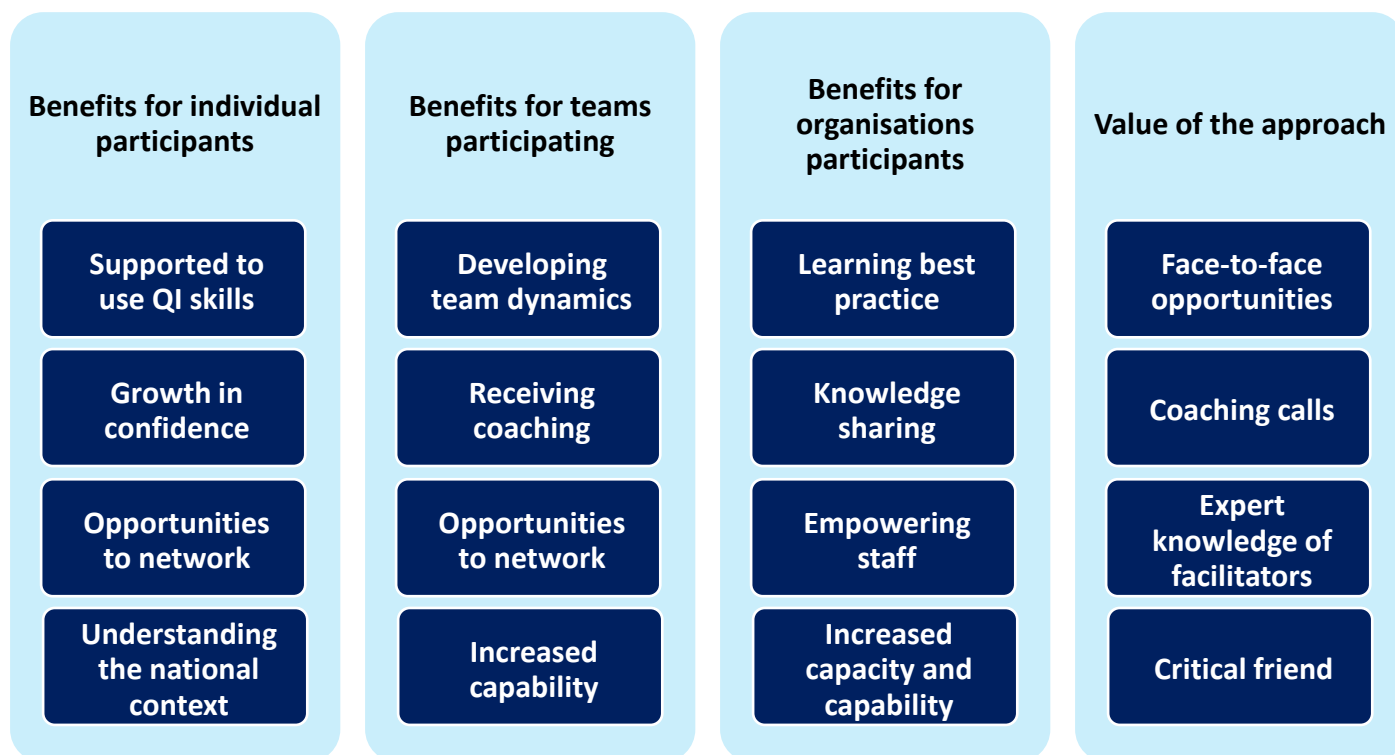
With the support of Evidence and Evaluation colleagues (EeviT), interviews were conducted in May 2024 with five participants covering all three of the participating teams. Here are selected insights from the interviews:

The tables below show the results of the thematic analysis of the interviews, broken down into themes and subthemes. The themes are:

- benefits for the individuals who participated in the programme
- benefits for the teams who participated in the programme, and
- benefits for the organisations who had staff participating in the programme.

Suggestions made by the interviewees around future considerations were also gathered to help inform future offers of improvement support.

Figure 1: PDS Improvement Support Programme impact summary: key themes



Representative quotations have been used for each subtheme. The quotations have been edited to improve readability and maintain confidentiality for the interviewees.

Theme one: benefits for individuals participating

Subtheme	Description	Representative quotations
Quality improvement skills	Individual participants stated they had learned new skills and give specific examples around data. Participants highlighted the tools they were given and supported to use as an advantage of the programme.	“...so I think (...) less would have happened if we weren't part of the programme, so being part of the programme did mean that some things did happen that otherwise wouldn't have.”
Confidence	Individuals felt that with learning and improved knowledge came the confidence to try new things.	“...it's been really nice to see staff grow over the past year in confidence and in the education that they are delivering.”
Networking	Participants highlighted benefits of making connections through the programme. Peer support was also highlighted as having been invaluable.	“It also meant that we were able to think outside the box and link up with other services that we hadn't done previously.”

Subtheme	Description	Representative quotations
Understanding the national context	Participants talked about becoming more aware of national strategies and strategic planning and how they could apply them locally.	“I think we came away [from face-to-face sessions] feeling as if we're part of a national picture..... so we talked about it, sharing best practice, networking... it was actually really valuable ...”

Theme two: benefits for teams participating

Subtheme	Description	Representative quotations
Team dynamics	Learning together and using the tools together strengthened team bonds and supported team building, creating shared ambitions and a sense of ownership.	“The action plan, for example, has been very useful but I was surprised how useful it was in terms of team building. You know, I didn't really see that aspect, like people have been able to tick off things, tangible things that they've contributed to and put in their next things [annual development review], and then putting it in a time context, I think that's been very useful, that's giving everyone a real sense of ownership and brought us together...”
Networking and making connections	Peer support was mentioned and the benefits of sharing information and learning from each other.	“We're all aiming for the same thing, and we're all in the same boat, and it was, it... really brought us together and that was quite early on.”
Coaching	One of the benefits of the coaching calls was that if provided accountability, it helped the team to move projects on.	“...but the thing that did sort of keep it on track was knowing you had a <i>coaching</i> call, and they were really compassionate and supportive and <i>coaching</i> experiences.”
Increased capability	Teams learned the language around QI and QI techniques, they were given tools and supported to use them. They developed new skills and ways of working together and with partners and stakeholders.	“So, when this [QI] structure came on board, it meant that actually, right, let's stop doing a little bit of this and a little bit of that and let's follow through on things so that we can actually solidify our roles as practitioners and then you know that kind of gave us the confidence for [more focused, realistic work].”

Theme three: benefits for organisations participating

Subtheme	Description	Representative quotations
Learning best practice	Participants were able to make connections both with other programme participants and with others outwith the programme – the facilitators were able to connect to other stakeholders and areas of interest.	“And so, I've spoken quite a lot with [another participant], for a bit of peer support, I'm meeting with a member of her team tomorrow, just about a system that they have in place about their recordings and the.... use of staff time...”
Knowledge sharing	Participants highlighted the benefits of coming together face-to-face and examples of peer support and sharing of information.	“[other participant} kindly put me in touch with [other person] and that was really good. [They were] so helpful and knowledgeable about the kind of workforce and how their workforce were doing things, which then gave me more ideas of how we could implement similar ideas here.”
Empowering staff	One team highlighted how they had made connections within their area (their service area and neighbouring areas), with people they hadn't felt able to connect with before. They believed the programme gave them the confidence to do this and they felt empowered to participate in improvement work.	“Everybody's been engaged with the programme ... it built the team morale, it built team dynamics, it was just what was required at the right time. It was good.”
Increased capacity and capability	Participants reported that they felt the foundations had now been laid, they had gained knowledge and understanding and now could take things forward themselves.	“...the reason that we applied to be part of the programme was to...ensure that we were delivering high quality post-diagnostic support and with Healthcare Improvement Scotland support, I feel that we've been given the right tools to be able to do that.”

Value of the approach

Subtheme	Description	Representative quotations
Face-to-Face	While most people appreciated the face-to-face aspect of the programme and the sense of buy-in that generated, some felt the pressures of taking time out of their busy days and didn't feel they wanted to travel.	“I do think the face-to-face, you know having that, that really was a catalyst, for the whole team. You know, I was doing the majority of coaching calls. I got great benefit. [Other team member] was doing a lot of them as well, but you know, translating that to the rest of the team without that face-to-face would have been a lot more difficult, lot more complex, we wouldn't have been so successful”
Expert knowledge	The expert knowledge and understanding from the Healthcare Improvement Scotland facilitation team was highlighted multiple times. Staff were found to be approachable, supportive and available to help as required.	“It's probably obvious, but I think needs mentioned is the really high level of knowledge of dementia and post-diagnostic support of the Healthcare Improvement Scotland team and ...of improvement methodology. But also, I think that needs to be underpinned with the expert knowledge and that's very evident and with the Healthcare Improvement Scotland team...”
Critical friend	Participants felt they could approach the Healthcare Improvement Scotland facilitation team with any questions or queries.	“We can bounce off somebody from Healthcare Improvement Scotland.”
Coaching calls	The benefits of the regular coaching call, for its support and its accountability, was highlighted by everyone interviewed.	“So, the coaching calls were really beneficial for us and within the team because it gave us a better focus and it made us all kind of realise how important we were individually to... the team...”

Methods

The PDS Improvement Programme tested a different way of working when supporting selected community sites to improve PDS and care co-ordination for people living with dementia and carers in the community⁵. Due to the brief duration of the support, we focused on creating the conditions for change and laying foundations for ongoing improvement work.

We took a flexible approach to supporting teams based on our capacity of one full time senior improvement advisor and one part-time improvement advisor. We adapted the type of quality improvement support normally offered in lengthier, commissioned programmes and made it more bespoke, shorter in duration and lighter in touch. This meant:

- selecting a small number of PDS teams - three teams
- providing the support for 1 year only
- focusing the time on creating the conditions for improvement
- focusing on individual team priorities
- ensuring monthly reporting was brief
- keeping any data collection simple and easy to collect
- tailoring support when progress was slow or disrupted because of service pressures or when more support was required
- going at a pace that suited each site
- being available at any time through email, and
- offering more of a coaching approach to teams to help create the conditions for change and for identifying and achieving their improvements.

We supported the teams to apply Quality Improvement (QI) methodology (using the [Model for Improvement](#)) and QI tools and techniques. We supported the teams to develop:

- a project charter to describe their individual improvement projects and create a shared understanding of its goals, objectives and resource requirements
- a driver diagram to help teams develop and communicate their change theory and how their improvement goals would be achieved
- a measurement plan
- an action plan
- a user journey map, and
- an impact story.

⁵ <https://ihub.scot/improvement-programmes/dementia/dementia-care-co-ordination/>

Future considerations

Participants highlighted three areas to consider as part of future work.

1. Continue the coaching element, networking and the light touch model

Support for a longer period, potentially tailing off towards the end, as some people felt the programme was too short to see changes. It was reported that the light touch approach helped reduce the intensity of the programme.

“It’s a shame that it comes to an end.”

2. Operational pressures

Operational pressures meant that some areas couldn’t put as much time to the programme as they would have liked – a longer programme might have helped that.

3. Further learning

Participants suggested areas for further learning.

- a) Consideration of the structure of teams taking part might be helpful. For example, team members may have different employers and may be managed in different ways.
- b) The focus on the importance of collecting data was highlighted as extremely beneficial and further support around this would be appreciated.
- c) Making connections was seen as extremely beneficial and made people feel they were part of a bigger picture, part of a national picture, and less isolated.
- d) Suggestions for Healthcare Improvement Scotland to look at future training needs of staff to fit with national strategies and guidelines.

Conclusion and next steps

By providing and testing this different way of delivering improvement support, it has shown the benefits of supporting teams to apply QI methodology using a light touch approach, and the benefits of its application.

It also highlighted the challenges of such a short programme and what could be improved or be different for future programmes. It demonstrated that a continued focus on improving dementia PDS and care co-ordination is highly valued by PDS teams and is essential to improve the quality-of-service provision and outcomes for individuals newly diagnosed with dementia, their carers and staff.

With numbers of people with dementia expected to double in the next 25 years, delivering good quality PDS and co-ordinated care has never been more crucial. There is now considerable expertise and knowledge on what works in a Scottish context to improve PDS and care co-ordination for people with dementia. However, without support for implementation, practice will remain variable. It is vital there is a continued national focus to improving PDS and care co-ordination.

Learning from this programme will inform Focus on Dementia’s future PDS and care co-ordination improvement support offers and other national and local improvement work.

Acknowledgements

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To learn more about Healthcare Improvement Scotland's dementia improvement programmes, visit [our webpages](#) or email his.focusondementia@nhs.scot.

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