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Post-Diagnostic Support in Primary Care for People Living with Dementia

Post-Diagnostic Support Improvement Programme Overview 2018-2022

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Introduction

Background and Overview

Every person with a new diagnosis of dementia in Scotland is entitled to a minimum of one year of post-diagnostic support (PDS) from a named person who will work alongside the person and those close to them[1].

Alzheimer Scotland's Five Pillars Model of PDS[2], pictured below, provides a framework for this support.

In March 2018 Focus on Dementia began working with three GP clusters – Shetland, East Edinburgh and Nithsdale in Dumfries and Galloway – to test the relocation, or closer alignment, of dementia diagnosis and PDS into primary care. The work with Nithsdale and Shetland concluded in March 2021, with the East Edinburgh programme concluding in March 2022. This report provides a summary of learning and outcomes from the programme.

The PDS in Primary Care programme was commissioned by Scottish Government. Each selected site was supported to innovate in order to allow for a greater range of learning from aspects of delivery that best suited local contexts. This resulted in the following changes:

- Nithsdale testing nurse and occupational therapist-led dementia diagnosis and locating this in clinic in GP surgeries
- East Edinburgh delivering pre- and post-diagnostic support and PDS group-work from their surgeries, and
- Shetland's nurse-led diagnosis assessment service being completed by a discrete PDS practitioner.

Our animation 'Focus on Dementia: Connecting dementia support to primary care' summarises the key activities.

Blake Stevenson Ltd, an independent social research company, were commissioned by Scottish Government to externally evaluate the work.

Context

As part of Scotland's third national dementia strategy, it was proposed that the relocation of dementia post-diagnostic services into primary care was tested in three areas of Scotland to see if and how this might work and if it made post-diagnostic dementia services more accessible and normalised for individuals and families. Such supports are mostly delivered from community mental health teams so this test also explored if basing such supports in primary care encouraged more people to come forward earlier for a dementia diagnosis or for a memory assessment.

Following a rigorous application process, Nithsdale, East Edinburgh and Shetland clusters were selected as the programme test sites. The selection of these sites offered the opportunity to test the programme across areas of contrasting population density and rurality.

Four aims for the programme were set out:

- implement and evaluate the delivery of dementia PDS from the three GP cluster sites, engaging the wider primary care team, social work, housing and the voluntary and independent sector
- understand which groups of individuals benefit from connecting dementia support to primary care, demonstrating those benefits and the scope for delivery of improved outcomes
- understand the distribution of need and demand for PDS within the primary care setting, and
- assess the cost and benefits of this approach to individuals and to health and social care systems.

While the programme would not remove the need for referral into specialist diagnostic services in many cases, it was anticipated that once a diagnosis was confirmed, management of the individual's care and support would sit in primary care led by a dementia PDS practitioner. The dementia PDS practitioner would use the Alzheimer Scotland 5 Pillar Model to enable the individual and their family to develop a personal plan that would support each person to live well and independently with dementia for as long as possible. Having a practitioner located within the cluster, or closely affiliated with it, would also give GPs reassurance that, should they diagnose a patient or refer on for diagnosis, there are dementia PDS services on hand to respond to their patient's needs after diagnosis.

It was also anticipated that dementia PDS practitioners would have a role within a GP cluster in the areas of raising awareness about the service, pre-diagnostic work and taking forward innovative approaches such as primary care-based Memory Clinics and PDS group-work.

The anticipated benefits to the three GP clusters becoming innovation sites were:

- ensuring GP cluster patients get quality care and support at the right place at the right time
- access to dementia specific training from NHS Education for Scotland (NES)
- support to test and evaluate the new approach of delivering PDS from a primary care setting
- direct access to a dedicated practitioner having specific knowledge and expertise of dementia and PDS
- direct access to individual personal plans developed with the person and their family carers with support from the PDS practitioner
- encouraging closer links between primary care and specialist secondary mental health care services to ensure a timely and accurate diagnosis
- access to dedicated funding to support the test work
- support with routine data collection and analysis, and
- transferable knowledge, skills and experience which can be shared with colleagues locally and nationally.

The anticipated benefits to people with dementia, their families and carers of receiving PDS from primary care were:

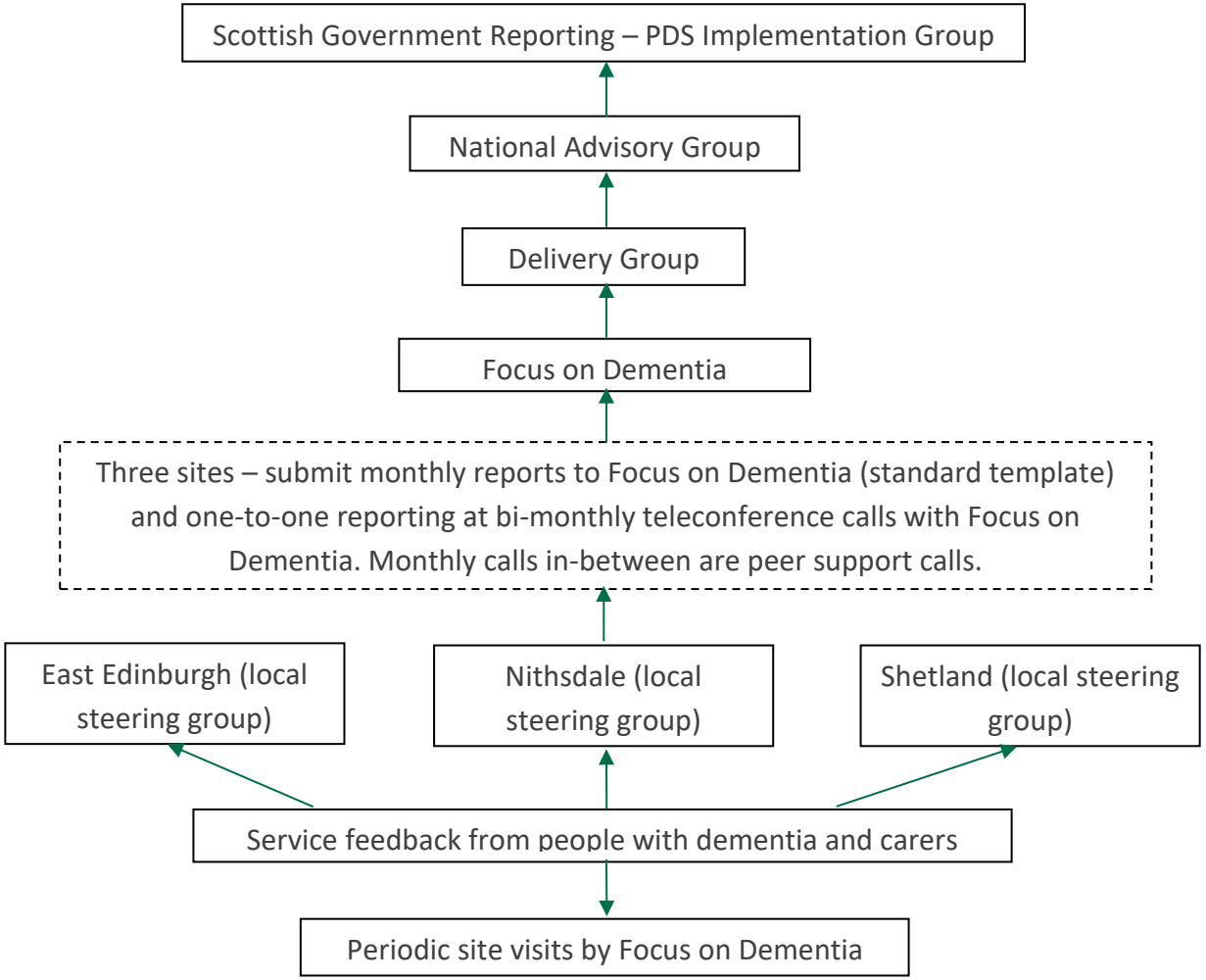
- support being readily accessible from a local and familiar environment
- support from staff who have a relevant understanding of dementia for the role they are in
- access to a timely diagnosis
- support to maintain community connections and peer support
- support to develop a personal plan that helps with self-management and informs future care, and
- support to make practical arrangements for the future.

Methodology

Focus on Dementia allocated the time of an improvement advisor and senior project officer to facilitate the programme. In the initial application and selection process Focus on Dementia ensured that each site had identified someone locally who had the skills and expertise, and who would be given dedicated time to project manage the initiative and liaise with and report to Focus on Dementia on its implementation and progress.

NES and Alzheimer Scotland were key partners in the programme as members of the programme delivery group (see reporting structure below). NES and Focus on Dementia also supported the fulfilment of the dementia education requirements of the primary care site staff in relation to Scotland's Promoting Excellence Framework. Healthcare Improvement Scotland's Data Measurement and Business Intelligence unit (DMBI) supported the measurement aspect of the programme.

Reporting Structure Applied to the Programme



Quality Improvement

Each site was supported to implement quality improvement tools to support their respective projects. They each produced a driver diagram, project charter, measurement plan, and customised and populated a data collection workbook. They submitted monthly progress reports to the improvement advisor and attended monthly meetings together to discuss progress with alternate meetings dedicated to peer support from the second year of the programme. Shared learning, progress updates, improvement ideas and action planning were also generated through three quality improvement learning sessions. This was an important aspect for sites, allowing them to continually innovate and explore opportunities to change systems and processes as their knowledge and experience increased.

The Quality Improvement Framework for Post-Diagnostic Support in Scotland

The Quality Improvement Framework self-assessment, which sets out the criteria for high quality post-diagnostic support for people living with dementia, was completed by Shetland to help establish their new service and by Edinburgh to assess their service pre- and post-pandemic, with improvement plans implemented at both sites.

The Impact of COVID-19

During the COVID-19 pandemic the Focus on Dementia programme of work went into hibernation for six months to ensure that there was no additional pressure placed on frontline services. The pandemic had a significant impact on Nithsdale and Shetland's activities throughout 2020 as key staff from those sites were recalled to frontline duties and recruitment for vacancies was put on hold. The programme recommenced in September 2020 and, due to the impact of COVID-19, the Scottish Government gave a further year of funding to East Edinburgh until March 2022. This allowed them to focus on the sustainability of their model, exploring the potential to spread to another cluster and delivering virtual PDS groupwork sessions.

Delivery and Impact

This section provides a summary of the delivery and impact from each site in turn. The narrative presented throughout this section draws on Blake Stevenson's external evaluation findings.

East Edinburgh

The East Edinburgh cluster is one of two GP clusters within the North East locality of the Edinburgh Health and Social Care Partnership (HSCP).

Delivery

East Edinburgh cluster created a dementia and memory support service with the role of a dementia support facilitator (DSF), delivering a service based in primary care that provided PDS for people with dementia and memory impairment living at home. It addressed the known gap in support for those registered by GPs as having mild cognitive impairment (MCI) which was impacting on daily living, who are often unable to access support without a dementia diagnosis.

Impact

The East Edinburgh innovation site showed how a peripatetic worker based in the practices with a good working relationship with primary care staff and access to GP systems and clinical records can provide a bespoke service pre- and post-diagnosis for patients in the cluster.

The work of the dementia and memory service led to:

- **High PDS uptake:** The process for identifying those newly diagnosed with dementia and recorded on the GP lists means that no-one was missed for PDS as the DSF could regularly check the GP lists at each practice. When offered PDS endorsed by the person's GP, engagement and take-up of the dementia and memory service was high at 94%.

- **An improved experience of PDS for people with dementia and carers:** From the one-to-one support to the PDS groupwork, the DSF raised awareness of what support was available to people, helped them to understand what was happening and connected them to others in a similar situation. Alongside the emotional support from the DSF, people were given practical support about changes that they might need to make in the home, advice about future care and help to access financial assistance and resources.

- **Improved confidence of primary care staff in supporting people with dementia:** The DSF's close working with primary care staff and training opportunities led to staff with increased knowledge of dementia care and support and a better awareness of specific support offered to patients. The DSF's presence in the practices meant they were on hand for GPs and practice staff for advice.

- **Reduced need for GP support among people with dementia and carers:** The DSF undertook much of the social, emotional, and practical support that GPs often need to address during appointments, leaving them freer to focus on medical issues. The GPs had a good understanding (from viewing the patients' notes) of how the DSF was supporting their patients. GPs were reassured that the patients' other needs were being addressed, which became even more acute during COVID-19.

- **Opportunities to develop additional areas of activity that benefit people with dementia and their carers:** The relationship-building and effective working improved the connections and transitions for people with dementia and their carers, whether with the memory assessment teams or third sector organisations. The offer of PDS groupwork, both face-to-face and virtually, widened engagement and support for carers and people with dementia.

Nithsdale

Nithsdale is one of five localities in Dumfries and Galloway and has a higher population and expected prevalence of dementia.

Delivery

Delivery at this site took a phased approach, first testing a new diagnostic pathway and then trialling a new approach to PDS. The key aims of their changes to PDS were greater flexibility and responsiveness to ensure people accessed the right support at the right time and to tackle increasing waiting times.

The implementation of the phased approach was significantly delayed by several factors, most notably by personnel changes and COVID-19. Due to these delays, activity remained focused on the diagnostic pathway throughout the test programme.

Impact

Nithsdale progress can be summarised as:

- **A reduction in wait times to be seen for assessments and diagnosis:** Nithsdale tested the delivery of dementia assessment and diagnosis clinics located in three of the nine GP practices in the cluster. Mental health nurses and occupational therapists were trained to undertake assessments and to make and deliver dementia diagnoses in these clinics. This upskilling of other dementia practitioners reduced reliance on psychiatrists and reduced psychiatrist time. Prior to the introduction of this model people were waiting, on average, nine months to be assessed. With this new model the wait time was reduced to 53 days.
- **Closer links between primary care and specialist mental health services:** This ensures timely and accurate diagnosis. This is largely as a result of the choice of innovation site. A GP practice-based clinic for diagnosis was perceived to have enabled increased communication between these services. While this clinic had to cease during COVID-19, Nithsdale are determined to maintain and build on connections with primary care.
- **A sustainable and transferable framework for PDS in Dumfries and Galloway**: With the new diagnostic pathway and work to improve PDS continuing as part of Dumfries and Galloway's sustainability and modernisation (SAM) programme, wider and sustained change should be achieved.

Shetland

The Shetland cluster covers 16 inhabited islands and is coterminous with Shetland HSCP.

Delivery

The Dementia Assessment Service (DAS) was established in Shetland in 2010. It is a nurse-led model, where, following referrals from GPs, nurse practitioners assess patients for dementia, make diagnoses and formulate treatment plans.

The opportunity to become an innovation site enabled Shetland HSCP to consider an approach that would improve PDS and increase uptake. They created a new role, the Dementia Support Practitioner (DSP), dedicated to leading the delivery of PDS in Shetland. The DSP was co-located with the DAS team and worked closely with them to provide a seamless link from diagnosis to PDS.

Impact

The introduction of the DSP role complemented the work of the DAS team and resulted in increased uptake of PDS and reduction in the length of time that people had to wait for PDS. It also resulted in a number of other benefits:

- **Improved experience of PDS among people with dementia and carers:** PDS was delivered in a more structured and consistent way than before. Recipients of the support reported that the DSP provided practical support and advice that helped them to live well with dementia, as well as support in liaising with other services, planning for the future and addressing carers' own needs. The support was reassuring for people with dementia and carers and this helped to reduce the stress and anxiety involved with managing the condition.
- **A significant positive impact on other services**: In some cases, professionals in other services reported being more aware of dementia diagnosis and PDS services. There were also examples of where the DSP helped professionals to enhance their knowledge and skills in supporting people with dementia and carers. In addition, by supporting service users with the social, emotional, and practical aspects of dementia, the DSP helped other health and social care services, including GPs and allied health professionals, to achieve greater efficiencies with their time.
- **Close collaborative working, co-location with the DAS team and the DSP's personal skillset and approach**: While these have been positive aspects associated with the programme, the DSP's sole practitioner status provides a barrier to sustaining these benefits. This can

affect continuity of support if the post-holder was absent for any reason. There also remains a need to do further work to engage and inform GPs of the DSP's role.

Considerations

The three innovation sites pursued very different approaches to testing the relocation of PDS within primary care clusters. The local setting and infrastructure shaped delivery and, although one site focused on diagnosis rather than PDS, there were common themes to the delivery of dementia care and support. The work of the three sites provides insight regarding how PDS could move towards a primary care model, and the potential benefits of this approach.

Impact on People with Dementia and their Carers

The innovation sites have showcased how aspects of dementia care and support can be effectively delivered within a primary care setting. In Nithsdale and Shetland the changes to the diagnostic pathways have shifted from the traditional psychiatrist dependent approach to a more streamlined and timely diagnosis process. Also, in Shetland, nurse-led diagnosis was followed by a seamless referral on to PDS.

As a result of these service changes, the accessibility of PDS was high in both Edinburgh and Shetland, and the processes in place meant that nobody slipped through the net. In Edinburgh, the support to people with MCI encouraged more people with memory worries to come forward and then proceed to dementia assessments, potentially at an earlier point. For both Shetland and Edinburgh, uptake of PDS was also high.

Feedback from participants indicate that this provision has led to more opportunities to access PDS and a better quality experience. In Edinburgh, the use of technology and the adaptation of provision meant that the PDS service continued for patients in the cluster during the COVID-19 pandemic. This was a lifeline for many who faced isolation with so many services forced to close.

Impact on Primary Care Staff and Settings

Across the innovation sites dementia awareness training was delivered to practices, and other training and support given on the assessing and diagnosing dementia. This increased awareness of dementia and improved knowledge of the diagnostic process. It also helped build knowledge of the support and care that could be provided to help individuals understand the illness, live as well as possible and plan for the future.

Practice staff acknowledged an increased confidence in referring and caring for people with a memory concern or dementia. In Edinburgh, GPs noted an improved understanding of the support being provided to the person with dementia which was not only reassuring but also helped them to provide relevant support to their patients.

Communication and awareness-raising materials informed dementia enabled changes within the physical environment in some premises and more generally raised the profile of dementia amongst those attending clinics and practices.

Impact on Local Policy and Practice

In each site the collaboration with others working across primary and secondary care and public and third sector agencies helped to improve the co-ordination of services. In some instances the worker or service helped to shape or join up local approaches to care so that across those teams supporting people with dementia their work complemented and enhanced rather than duplicated effort.

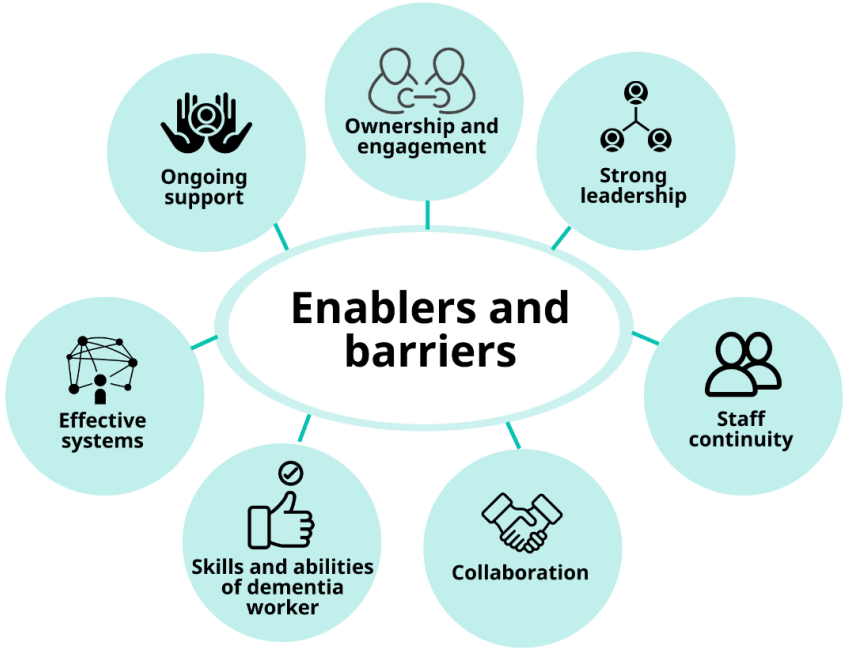
In Shetland, the diagnostic pathway and onward referral to PDS is well established and more work with practices will enhance understanding further. In Nithsdale the dementia diagnostic pathway has impacted on board-wide policy and will be rolled out across the region.

Costs and Benefits

Data ownership and restrictions meant it was not possible to explore the costs of a primary care model versus a traditional one. However, economic analyses of the diagnostic pathways in both Shetland (under the nurse-led model) and Nithsdale (under the dementia practitioner led model) were encouraging. For Shetland savings were identified of between £380 and £650 per diagnosis and for Nithsdale between £56 and £134 per diagnosis.

Enablers and Barriers

Across all three sites there were common success factors and barriers to delivering the services.



When there was **ownership and engagement** of key stakeholders, the service was championed and supported. The engagement of GPs was particularly crucial with their buy-in a critical element of the practice-based model. They could promote the service, refer people, understand the benefits and support offered and access information related to the patients. It was not possible to progress any service without GP engagement and support.

In Edinburgh, the **strong leadership** of the steering group meant implementation and delivery remained in focus with no mission drift or gaps in provision when personnel changed. Crucial to the success of implementation and service delivery was dedicated project management support to develop the service, especially given the complexity of working across different practices.

As with any service, staff changes can cause disruption and this was the experience for all three, and Nithsdale in particular. With a sole practitioner as the lynchpin of the service any leave or sickness led to a gap in provision. In addition, new personnel could lead to a major change in approach so **staff continuity** was essential.

When the service worked well there were **effective systems** for reporting and communicating actions and support. This was demonstrated in Edinburgh with easy access to patient records to update information and in Nithsdale with strong administrative support ensuring the smooth operation of the GP based diagnosis clinics. Connection with GP systems was key to co-ordinating care and to understanding and reflecting on progress made.

Collaboration across teams and services led to better care co-ordination and the opportunities for this were enhanced by co-location with other teams or being based within primary care settings. This not only enabled effective relationship-building but also encouraged learning and knowledge exchange across teams and between individuals.

The **skills and abilities** of the worker were critical for effectively engaging people with dementia and carers and for providing appropriate person-centred support. In Edinburgh and Shetland the skillset of the workers was praised and the importance of having the right person in this post was clear.

Throughout the delivery period the innovation sites received **ongoing support** from Focus on Dementia's improvement advisor with regular monitoring and reporting to the team and opportunities for collaboration. This committed support was crucial in keeping the national programme on track and the sites engaged.

Spread and Sustainability

In Shetland the DSP role has been mainstreamed and become the established route for dementia care and support. While still reliant on key individuals, it is embedded within the system.

In Nithsdale the whole system has been reviewed and learning applied to later models. This means the primary care service was not dependent on a sole practitioner but supported by a team of practitioners who can co-ordinate care in a sustainable manner.

The East Edinburgh innovation site had a clear impact on people with dementia and their carers, GPs and practice staff, and on the wider services designed for those affected by dementia. This site received extended funding from the Scottish Government PDS expansion monies to deliver their service for a further two years. The DSF is now part of the Older People's Mental Health Team but retains the role of working exclusively with the East Edinburgh cluster and can continue to access the GP patient records.

Conclusions

The innovation sites delivered their services during an unprecedented time and when people with dementia and their carers have experienced real difficulties in accessing a dementia diagnosis and PDS. Each site has informed actions and decisions within its locality and the learning has highlighted what works, what has been a challenge and the critical elements for success. Lessons from the innovation sites reflect key elements of the dementia journey and should be considered by those looking to improve the quality and experience of dementia care and support. The Blake Stevenson evaluation states that service deliverers and commissioners should reflect on:

- the benefits and approach to supporting people with MCI
- how an effective local diagnostic pathway that was nurse-led or dementia support worker-led, corroborated by the psychiatrist, could lead to timely assessments within a community clinic or practice
- a referral to a link worker based within primary care who can co-ordinate the support in close liaison with the GP, and
- the need for appropriate communication systems to ensure that the GP was aware of the care that patients receive and, once PDS ends, the person's personalised plan was retained within the practice records.

Additional Benefits

Throughout the programme Focus on Dementia identified opportunities to learn from other dementia in primary care initiatives such as collaborating with the Alzheimer's Society about their Dementia Friendly General Practice toolkit (DFGP) initiative. The Alzheimer's Society generously shared information on this work with the clusters, and other interested parties from primary care, via a webinar on 29 November 2017. As a result of this liaison the Alzheimer's Society agreed to share their toolkit with Focus on Dementia and Alzheimer Scotland to support production of a Scottish version. This Alzheimer Scotland and Healthcare Improvement Scotland co-produced resource is available to all Scottish GP practices. The three sites were involved in the production and testing of this resource, a guide to making general practice dementia friendly.

Another collaboration was with representatives of 'The Golden Ticket' approach in East Sussex who presented a webinar for our sites and others on their highly successful dementia initiative on 19 March 2018. This approach piloted by Buxted Medical Centre, is about working with a range of partner agencies to provide a co-ordinated package of support for people with dementia and their carers. It includes a primary care worker, medication reviews and a weekly clinic. Over 50 people tuned into this webinar.

Another Focus on Dementia led piece of work that relates to the overall improvement of PDS in Scotland is the development of the aforementioned Quality Improvement Framework for Dementia Post-diagnostic Support. Developed in collaboration with PDS practitioners and by listening to people with dementia and carers' experiences, the framework identifies what a good PDS service looks like and helps services to make improvements in how they deliver support. A version for people with dementia and carers 'making the most of your post-diagnostic support' was also produced. The Quality Improvement Framework is now in its second edition and has benefitted from the learning from the PDS in Primary Care programme as criteria about linking PDS practitioners to primary care and improving communication with GP practices has been added.

Further information about the programme including the animation, case studies and the recorded interviews can be viewed on the Focus on Dementia webpages.

The findings from this programme are also informing subsequent commissions from Scottish Government to Focus on Dementia to spread the improvements to community supports concerning diagnosis, pre- and post-diagnostic support and care co-ordination.

Outputs

The learning from all of the work from this programme is being shared through a variety of methods including:

- recorded interviews with programme leads for each area
- the animation to explain key points from the programme and each of the sites
- a case study about virtual groupwork
- a case study from a GP practice in Benbecula on using the associated Dementia Friendly General Practice Guide

- a poster at the Alzheimer Disease International Conference in London 8-11 June 2022, and
- Focus on Dementia ran a Twitter campaign 20-24 June 2022.

Acknowledgements

Thank you to everyone who supported the delivery of this work including people living with dementia and their carers, staff across East Edinburgh, Nithsdale and Shetland, colleagues in Healthcare Improvement Scotland and colleagues in our partner organisations.

References

1. Scottish Government. National dementia strategy: 2017-2020 [online]. 28 Jun 2017 [cited 17 Aug 22].

2. Alzheimer Scotland. 5 Pillar Model of Post Diagnostic Support [online]. 2015 [cited 17 Aug 22].

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