Evaluation of the Primary Care Dementia Innovation Sites:

Final Report - September 2021

Blake Stevenson Ltd

Contents

List of acronyms

ACE iii – Addenbrooke’s Cognitive Evaluation

ACP – Anticipatory Care Plan

AHP – Allied Health Professional

CMHN – Community Mental Health Nurse

CMHT – Community Mental Health Team

CPN – Community Psychiatric Nurse

DAS – Dementia Assessment Service (Shetland)

DLW – Dementia Link Worker

DP – Dementia Practitioner (Nithsdale)

DSF – Dementia Support Facilitator (East Edinburgh)

DSP – Dementia Support Practitioner (Shetland)

EMIS – Egton Medical Information Systems (clinical IT system used in some general practices)

HBMR – Home Based Memory Rehabilitation

HEAT – Health Improvement, Efficiency, Access and Treatment

HSCP – Health & Social Care Partnership

IDEAS – Interventions in Dementia, Education Assessment and Support

KIS – Key Information Summary

MATS – Memory, Assessment and Treatment Service (Edinburgh)

MCI – Mild Cognitive impairment

MoCA – Montreal Cognitive Assessment

OT – Occupational Therapist

PDS – Post-Diagnostic Support

PPE – Personal Protective Equipment

SAM – Sustainability and Modernisation

Vision – Clinical IT system used in some General Practices

Executive summary

In Scotland, there are around 90,000 people living with dementia.[1]

The Scottish Government published its first National Dementia Strategy in 2010, seeking to improve support, care and treatment for people with dementia, and their families and carers across all care settings. The strategy recognised that effective post-diagnostic support (PDS) was likely to improve their health and wellbeing and, in 2013, Scotland led the way by introducing the entitlement of at least one year of PDS for everyone newly diagnosed with dementia.

To improve the quality of PDS with a more flexible, person-centred, and accessible approach, the third National Dementia Strategy 2017-2020 committed to assessing the principle of relocating post-diagnostic dementia services in primary care.

In order to help meet this commitment, the Scottish Government commissioned Focus on Dementia, in partnership with NHS Education for Scotland (NES) and Alzheimer Scotland, to develop innovation sites that tested the relocation of dementia PDS to a primary care setting.

In April 2017, three innovation sites were selected - East Edinburgh in NHS Lothian, Nithsdale in NHS Dumfries and Galloway, and Shetland. While working towards the same overarching aims, these sites took different approaches to PDS in primary care.

Evaluation

In December 2018, the Scottish Government commissioned Blake Stevenson Ltd to evaluate the work of the three primary care dementia innovation sites and look at:

- strategies to increase the accessibility of dementia post-diagnostic services, increase the confidence of GPs responsible for making referrals for dementia assessments, and collaborative approaches
- enablers and barriers, and costs and benefits of this model
- the work of the innovation sites on completion of testing and the consolidation of changes
- the spread and sustainability of learning/good practice.

There were significant delays to the evaluation associated with the requirement for Public Benefit and Privacy Panel (PBPP) approval and the COVID-19 pandemic which meant that the fieldwork did not begin until two years after the evaluation was commissioned.

The methodology used to evaluate the innovation sites is summarised overleaf.

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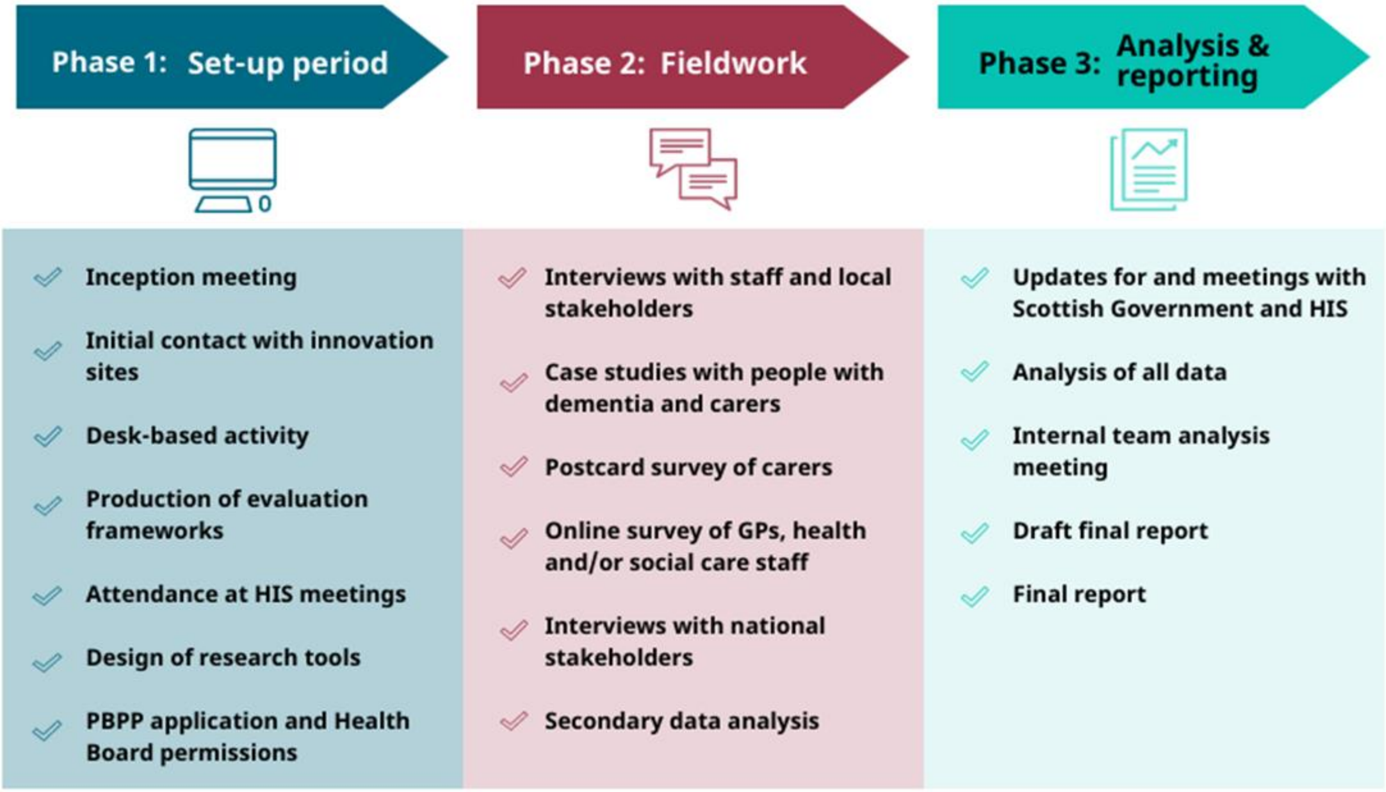
[1] based on the Eurocode prevalence model

Figure E1: Approach to the evaluation



Phase 1: Set-up period

- ✓ Inception meeting
- ✓ Initial contact with innovation sites
- ✓ Desk-based activity
- ✓ Production of evaluation frameworks
- ✓ Attendance at HIS meetings
- ✓ Design of research tools
- ✓ PBPP application and Health Board permissions

Phase 2: Fieldwork

- ✓ Interviews with staff and local stakeholders
- ✓ Case studies with people with dementia and carers
- ✓ Postcard survey of carers
- ✓ Online survey of GPs, health and/or social care staff
- ✓ Interviews with national stakeholders
- ✓ Secondary data analysis

Phase 3: Analysis & reporting

- ✓ Updates for and meetings with Scottish Government and HIS
- ✓ Analysis of all data
- ✓ Internal team analysis meeting
- ✓ Draft final report
- ✓ Final report

Key findings - East Edinburgh

The East Edinburgh cluster was one of two GP clusters within the North East locality of the Edinburgh Health and Social Care Partnership.

Delivery

A new Dementia and Memory Support Service would test 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 would address the known gap in support for those with mild cognitive impairment (MCI) who often cannot access support without a dementia diagnosis.

Impact

The East Edinburgh innovation site has shown 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 PDS service for patients in the cluster.

The work of the Dementia and Memory Service has led to:

- **Increased PDS uptake:** The process for identifying those newly diagnosed with dementia means that more people were identified for PDS. When offered PDS endorsed by their own GP, engagement and take up of the Dementia and Memory Service was high.

- **People with dementia/carers with an improved experience of PDS:** From the one-to-one support to the group work, the DSF has raised their awareness of what support was available, helped them to understand what was happening and connected them to others in a similar situation. Alongside the emotional support from the DSF, they were given practical support about changes that they might need to make in the home, advice about future care and what and help to access financial assistance and resources.
- **Primary care staff have improved confidence in supporting people with dementia:** The DSF's close working with primary care staff and training opportunities has 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 at most of the practices meant she was on hand for GPs and practice staff for advice.
- **Reduced need for GP support among people with dementia and carers:** The anecdotal evidence showed that the DSF alleviated the social, emotional, or practical support that GPs often needed to address during appointments, leaving them free to focus on medical issues. The GPs had a good understanding (from viewing the patients' notes) of how the DSF was supporting 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 has improved the connections and transitions for people with dementia and their carers, whether with MATS or third sector organisations. The offer of group work, both face-to-face and virtually, has widened engagement and support for carers and people with dementia. The potential extension of the service to another cluster and the possible work in care homes means that the service was branching out and could have an even wider impact.

Key findings – Nithsdale

Nithsdale was one of five localities in Dumfries and Galloway and, with a higher population and expected prevalence of dementia, it was identified as an ideal PDS innovation site.

Delivery

This site took a phased approach, first testing a new diagnostic pathway and then trialling a new approach to PDS. The key aims of changes to PDS were more flexibility and responsiveness to ensure people accessed the right support at the right time and 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 evaluation's lifetime and although changes were made to some elements of the support provided post-diagnosis, the formal PDS pathway (as set out within the Five Pillars Model) was not altered.

Impact

As innovation site activity in Nithsdale continues, it was expected that further change and impact will emerge beyond the lifetime of the evaluation. However, progress against key outcomes at this point can be summarised as:

- **Increase in number of people being diagnosed with dementia:** Although more people were diagnosed in 2019 than in 2018 in the areas where the test practices were located, only three out of the nine cluster practices participated in innovation site activity. With the limited available evidence, no robust conclusions can be drawn.
- **Primary care staff have improved confidence in supporting people with dementia**: Limited evidence available from the survey of practice staff indicates that both understanding of dementia diagnosis and confidence in referring and caring for people with dementia increased. However, the updated diagnostic pathway takes place outwith primary care and its implementation began outside the data collection period. It was therefore not known if further benefits beyond the initial test sites can be achieved.
- There are closer links between primary care and specialist mental health services to ensure timely and accurate diagnosis because of the innovation site: A practice-based clinic was perceived to have enabled increased communication between these services. But again, because of the absence of a presence in primary care in the current version of the pathway, it was unknown if and how these benefits will be maintained.
- **The innovation site results in a sustainable and transferable framework for PDS in Dumfries and Galloway**: If the new diagnostic pathway and work to improve PDS continues as part of the sustainability and modernisation (SAM) programme then wider and sustained change could be achieved.

Key findings - Shetland

The Shetland cluster covers 16 inhabited islands and was co-terminous with Shetland Health and Social Care Partnership.

Delivery

The Dementia Assessment Service (DAS) was established in Shetland in 2010. It was 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

Overall, the Shetland innovation site was a success. 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. Furthermore:

- **It improved the experience of PDS among people with dementia and carers,** with PDS delivered in a more structured and consistent way than before. Interviewees 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.
- **The DSP had a significant impact on other services**. In some cases, professionals in other services reported being more aware of dementia diagnosis and PDS services, and there were also examples 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 AHPs, to achieve greater efficiencies with their time. While there was no quantitative evidence of this, some interviewees reported that the DSP's role helped to reduce the length of appointments that GPs and AHPs had with people with dementia.
- **Close collaborative working, co-location with the DAS team and the DSP's personal skillset and approach** have been key success factors. Challenges have included the DSP's sole practitioner status, which can affect continuity of support if the post-holder was absent for any reason, a lack of engagement from some GPs, and uncertainty around the future of the wider DAS service.

Discussion and considerations

The three innovation sites pursued very different approaches to testing the relocation of PDS within primary care hubs. 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 for how PDS could move to, and the benefits of, a primary care model.

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. In Shetland diagnosis was followed by a seamless referral on to PDS.

As a result of the services, in both Edinburgh and Shetland the accessibility of PDS was high and the processes in place meant that nobody on the GP registers with a new diagnosis of dementia 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.

Comments from evaluation participants indicate that this provision has led to more opportunities to access PDS and a better quality experience. In Edinburgh, the service continued during the COVID-19 pandemic, which was a lifeline for many who faced isolation with so many services forced to close. By embracing technology and adapting the provision, PDS continued for patients in the cluster. A blended model for delivering PDS using some of these successful elements would be useful going forward.

Impact on primary care staff and primary care settings

Across the innovation sites dementia awareness training was delivered to practices and other training and support given on the diagnostic process from the Consultant Psychiatrist within the Focus on Dementia team. 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 patients 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

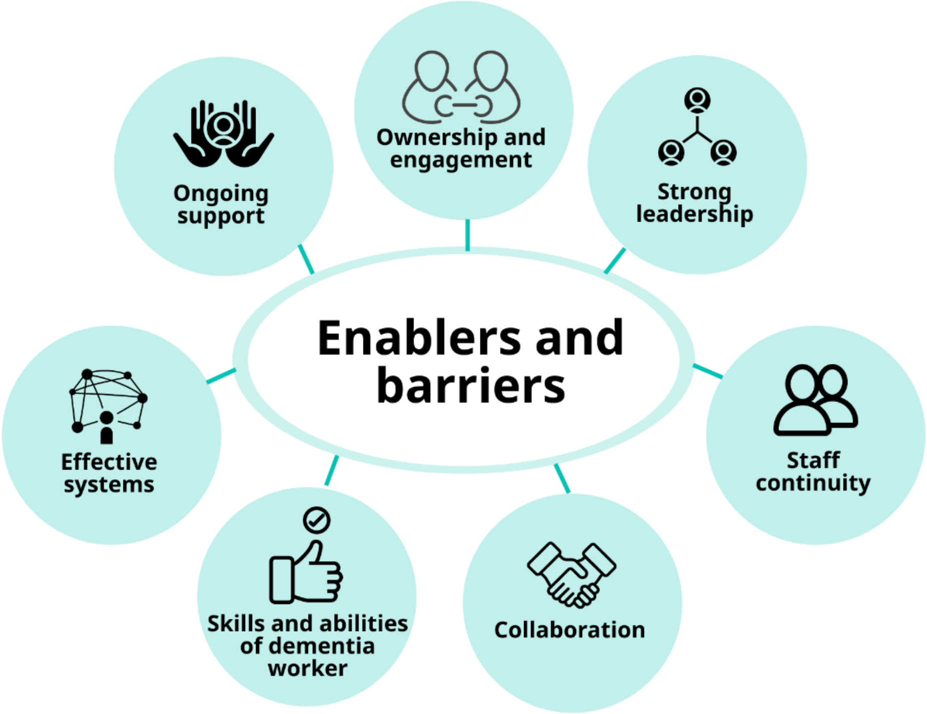
In each site the collaboration with others in primary and secondary care and public and third sector agencies helped to improve the co-ordination of services. In some instances the worker or service has helped to shape or join up local approaches to care so that across those teams supporting people with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

In Shetland, the diagnostic pathway and onward referral to PDS was 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.

The three innovation sites had the opportunity to share practice and learn from each other through the co-ordinating and supporting role of the Focus on Dementia team at learning events and knowledge exchanges. 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.

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 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. If the right staff are to be retained, the responsibilities and workload should be graded at a level commensurate with the role and on a par with other dementia link workers.

Throughout the delivery period the innovation sites received **ongoing support** from the Focus on Dementia Improvement Advisor. Regular monitoring and reporting to this team, opportunities for collaboration, and this committed support was crucial in keeping the national programme on track and the sites engaged.

Costs and benefits

Data ownership and restrictions means 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.

With this indicative financial saving, along with effective and timely diagnosis, other localities should explore how their diagnostic pathways could adopt some of these elements to improve their PDS.

The innovation sites were funded by the Scottish Government and although Shetland has mainstreamed the role from within their HSCP budget, the Edinburgh model operates on this short term funding. There is an opportunity to review this piecemeal approach and different funding sources for contracted PDS, community based support and the wider link worker programme across practices and then to explore the prospects and added value in existing resources to better link in with a primary care model.

Consideration should be given to working with those who deliver PDS to undertake a comprehensive cost consequence analysis of the various models of delivery in order to fully understand the costs and benefits of the service and any financial efficiencies. This would provide the business case for funding from other sources, for example primary care, if a quantifiable decrease of GP time and resources was evidenced. It would also help inform future commissioning decisions about the type, delivery model and cost of PDS.

Spread and sustainability

In Shetland the DSP role has been mainstreamed and become the established route for dementia care and support. Whilst still reliant on key individuals, it is embedded within the system. However, the future of the wider DAS was unknown and could impact on the sustainability of the DSP role. For the model to remain a success it now needs further promotion and awareness-raising amongst primary care.

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. Dumfries and Galloway's HSCP was leading a region wide Sustainability and Modernisation (SAM) programme. At the time of the evaluation's fieldwork, the project team were preparing to submit a SAM mandate as part of the planned care workstream. The testing and subsequent roll out of the new pathway was therefore expected to take place under the umbrella and the project team was aiming to bring about whole system change to provide a multi-disciplinary and co-ordinated approach to PDS.

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 innovation site has received extended funding from the Scottish Government to deliver their service until March 2022 and it was hoped that during this extension period a sustainable funding model can be identified for the service. Consolidation and further roll out would also require significant engagement of GPs, overcoming the logistical challenges of working within a cluster (including access to GP IT systems) and project management support.

Over the last four years the learning from these differing approaches has been shared by the sites and more widely by the Focus on Dementia team through many vehicles for exchanging insight and information with local and national stakeholders and this report adds a further element to the learning and innovation that can be shared.

Conclusion

The innovation sites have 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 the dementia journey and should be considered by those looking to improve the quality and experience of dementia care and support. 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 personalised plan was retained within the practice records.

1. Introduction

This report presents the findings from the independent evaluation of the dementia post-diagnostic support in primary care innovation sites.

Aims of the evaluation

In December 2018, the Scottish Government commissioned Blake Stevenson Ltd. to evaluate the dementia post-diagnostic support (PDS) service provided to patients across three primary care innovation cluster sites – Nithsdale in Dumfries and Galloway, East Edinburgh and Shetland.

The purpose of the evaluation was to recommend strategies to:

- increase the accessibility of dementia post-diagnostic services encouraging more people with memory worries to come forward earlier for dementia assessments and to take up post-diagnostic support should a diagnosis of dementia be made
- increase the confidence of General Practitioners responsible for making referrals for dementia assessments that referrals will be promptly followed by good quality, person-centred support to help individuals understand and adjust to the illness, live as well as possible and plan for the future
- encourage areas to link better through an improved collaborative approach including peer support and learning improvement sessions, webinars and sharing of practice with other innovative projects across the test sites.

In addition, as part of the analysis across the test sites, the evaluation also needed to:

- identify enablers and barriers in local areas delivering the services
- understand the costs and benefits of this type of model compared with delivering this type of service within a more traditional setting (community mental health setting)
- evaluate innovation cluster sites on completion of testing and the consolidation of changes in each of the three sites
- evaluate innovation cluster sites on the spread and sustainability of learning/good practice/innovation across Scotland.

Structure of the report

The remainder of this report is structured as follows:

Chapter 2: Background and context

Chapter 3: Findings: Delivery and impact Edinburgh

Chapter 4: Findings: Delivery and impact Nithsdale

Chapter 5: Findings: Delivery and impact: Shetland

Chapter 6: Discussion

Chapter 7: Conclusions and considerations

2. Context and Background

Dementia policy and landscape

In Scotland there are around 90,000 people living with dementia, based on the Eurocode prevalence model.

The Scottish Government published its first National Dementia Strategy in 2010, seeking to improve support, care and treatment for people living with dementia, and their families and carers across all care settings. The strategy recognised that effective post-diagnostic support (PDS) was likely to improve the health and wellbeing of people with dementia, be a good financial investment by service commissioners by delaying the need for intensive supports, and tackle people's fears about coming forward for diagnosis.

In 2013, Scotland led the way by introducing a Health Improvement, Efficiency, Access and Treatment (HEAT) Standard (formerly target) that everyone newly diagnosed with dementia was entitled to be offered, at minimum, one year's worth of post-diagnostic support co-ordinated by an appropriately trained Link Worker. This support, primarily non-medical, provided the person with dementia and their family with a dedicated, skilled practitioner to help understand and adjust to the diagnosis, connect with community resources and build a comprehensive, person-centred plan.

Whilst there has been progress on delivering the one year entitlement, the most recent data showed that in 2018/19, 43.4% of the estimated number of people developing dementia (the incidence) received a new diagnosis and were referred for PDS. 75.1% of these people successfully received PDS for a minimum of one year".

There is recognition by the Scottish Government and others that not enough people are getting access to support to live as well as possible with dementia and plan for the future and that this support can vary in quality.

PDS in primary care

The third National Dementia Strategy 2017-2020 emphasised the need to use community assets and grassroots initiatives alongside other dementia services, and to improve the quality of PDS with a more flexible, person-centred, and accessible approach.[2] To help deliver this, the strategy identified the potential value of relocating PDS into primary care.

While the relocation of PDS into primary care would not remove the need for referral into specialist diagnostic services, the management of an individual's care and support would sit in primary care, led by the Dementia Link Worker. These Link Workers would continue to use the 5 Pillars Model created by Alzheimer Scotland

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[2] http://www.gov.scot/Resource/0052/00521773.pdf

as a baseline, to enable the individual and their family to develop a robust personal plan that would support each person with dementia to live well and independently for as long as possible.[3]

To assess the principle of relocating post-diagnostic dementia services in practice, the National Dementia Strategy committed to "*test and independently evaluate the relocation of post-diagnostic dementia services in primary care hubs as part of the modernisation of primary care*".

In order to help meet this commitment, the then Scottish Government's Dementia Innovations Unit commissioned Focus on Dementia (the national improvement portfolio, based within Healthcare Improvement Scotland's ihub) in partnership with NHS Education for Scotland (NES) and Alzheimer Scotland, to develop innovation sites that tested the relocation of dementia PDS to a primary care setting.

Focus on Dementia invited Integration Joint Boards (IJBs) to support clusters to apply for two years of funding to pioneer approaches for post-diagnostic dementia support in primary care with the aim that:

- people with dementia will have access to PDS from a primary care setting
- people with dementia and their carers will experience high quality PDS from a primary care setting
- staff have improved knowledge, understanding and confidence in supporting people with dementia and carers.

The Focus on Dementia team would continue to support the innovation sites by building capacity through one-to-one sessions and improvement workshops, supporting them to gather data to understand and demonstrate changes that led to improvement and improving knowledge and skills in dementia.

Innovation cluster sites

In April 2017, three primary care settings across three sites were selected as innovation clusters. A review of their work and the resulting impact on the response to dementia in general practices would the provide evidence to inform future developments. While working towards the same overarching aims, these sites took different approaches for a novel strategy to PDS in primary care.[4,5] The three areas were East Edinburgh in Lothian, Nithsdale in Dumfries and Galloway, and Shetland.

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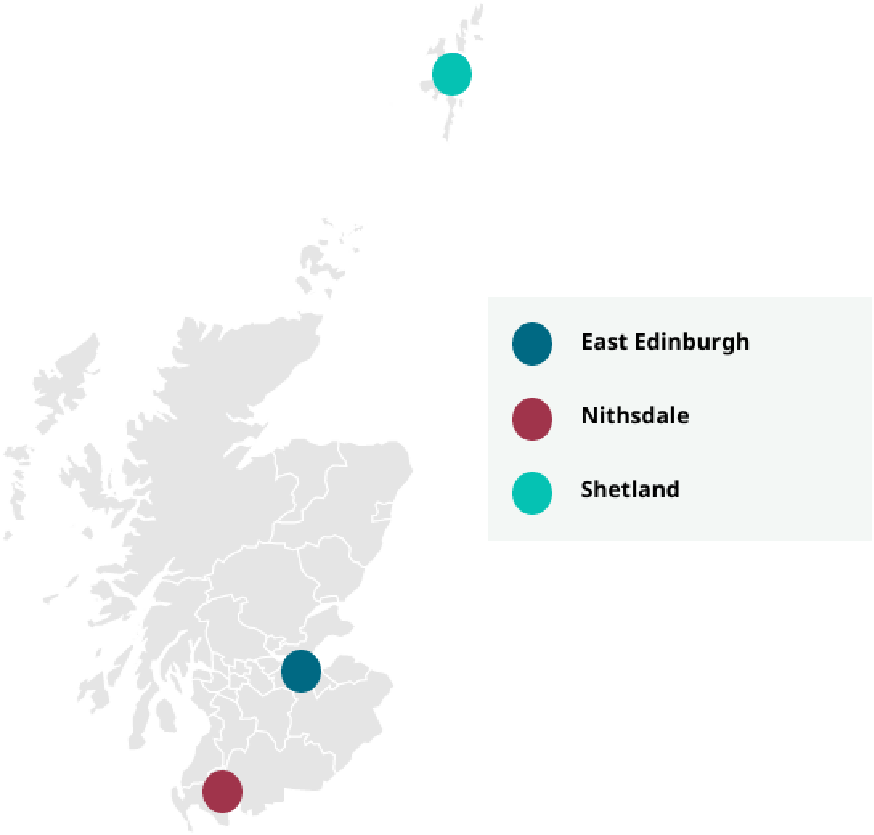
[3] https://www.alzscot.org/campaigning/five_pillars

[4] https://ihub.scot/media/1421/20180419-pds-in-primary-care-april-flash-report-v1.pdf

[5] https://ihub.scot/media/1462/20180628-fod-report-1-0.pdf

Figure 2.1 Innovation cluster sites



COVID-19

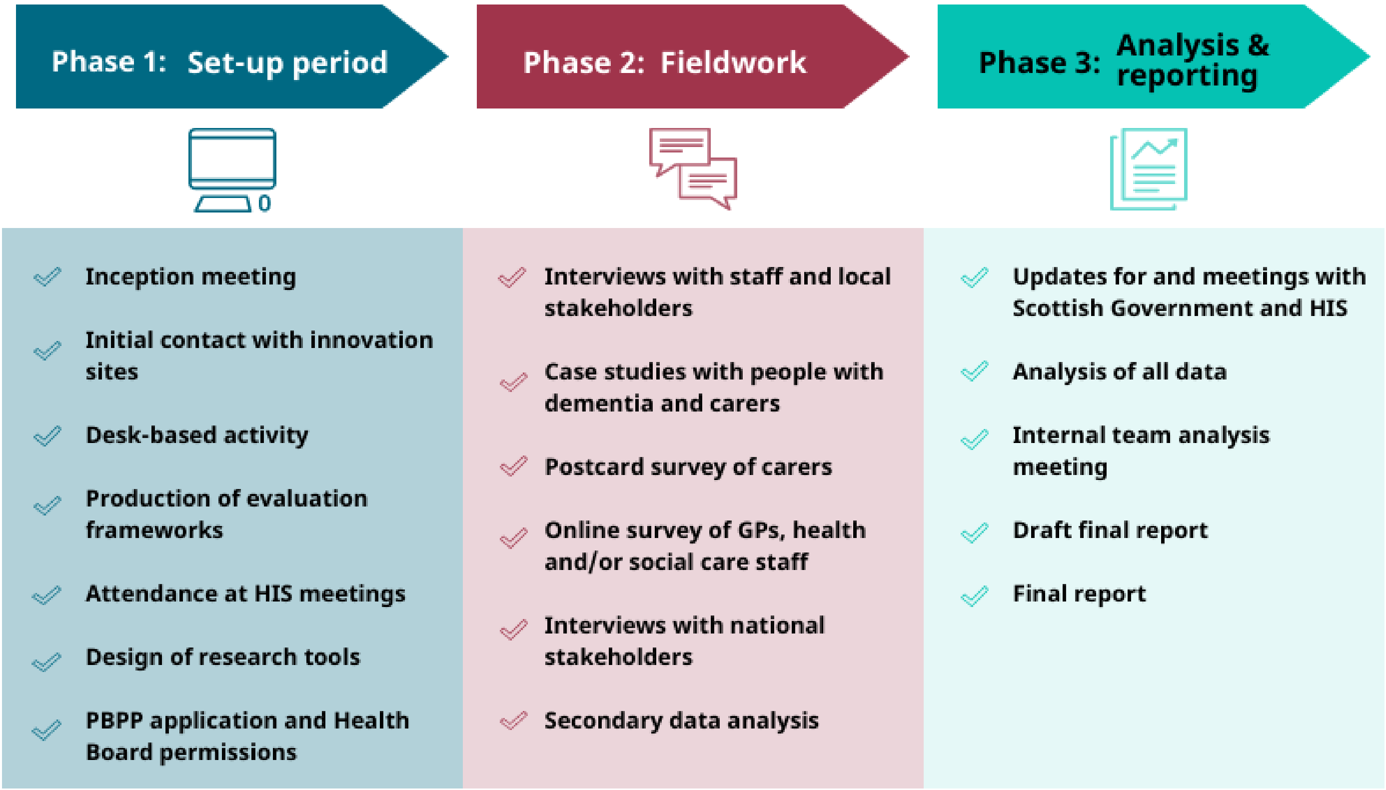
Plans to consult on a fourth National Dementia Strategy were necessarily put on hold due to the onset of the COVID-19 pandemic. The Scottish Government recognised that there would be unavoidable disruption to this and other projects while all sectors worked together to respond to the needs of people with dementia and their families in response to COVID-19. Building on this response, the Scottish Government's Dementia COVID-19 Recovery Plan was published in December 2020.

The plan recognised the challenges with accessing PDS and that the post-COVID-19 pandemic service was further impacted. It reaffirmed the continued support for the national one year PDS guarantee and committed to working systematically to assess current provision. It also looked at how services adapted during the COVID-19 pandemic so that the learning from using 'virtual' support and online tools could be considered as part of the future service offering.

Methodology

In the remainder of this chapter, we describe the approach that we employed to complete this evaluation. The diagram below summarises the methodology.

Figure 2.2 Methodology



Phase 1: Set-up period	Phase 2: Fieldwork	Phase 3: Analysis & reporting
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Desk-based activity	Postcard survey of carers	Internal team analysis meeting
Production of evaluation frameworks	Online survey of GPs, health and/or social care staff	Draft final report
Attendance at HIS meetings	Interviews with national stakeholders	Final report
Design of research tools	Secondary data analysis	
PBPP application and Health Board permissions		

We describe the key elements of our methodology in detail below.

Phase 1: Set-up period

The first phase involved initial contact and discussions with the three sites to gather details of the activity taking place and progress so far.

As part of our familiarisation with the work, we attended two events facilitated by HIS that brought together all the innovation sites and other services involved in delivring PDS. This gave an additional opportunity to meet staff from each of the sites about progress and discuss the arrangements for the evaluation.

To prepare for the design of the evaluation plans we reviewed background documentation including measurement plans and driver diagrams to enhance our understanding of the activity in each innovation site and then worked with the sites to refine the evaluation framework for each area. These listed the intended outcomes and the evaluation activities planned to gather evidence related to each. Where possible the plans included economic elements.

We developed research tools and privacy notices for evaluation participants which included surveys and interview schedules for various stakeholders.

Before the fieldwork could begin, we had to obtain approval from the Public Benefit and Privacy Panel (PBPP). We submitted our draft application to PBPP in May 2019 and, following delays for a number of reasons set out later in this section, we received approval in October 2020. We then confirmed approval with research and information governance teams in each of the health boards and began fieldwork in December 2020.

Phase 2: Fieldwork

Our fieldwork included interviews with local staff and stakeholders, service users and national stakeholders, as well as surveys of carers and health and social care staff. A total of 140 individuals contributed their views to the evaluation.

As a result of COVID-19 restrictions, all interviews took place remotely via telephone or Microsoft Teams.

Interviews with staff and local stakeholders at the innovation sites

We interviewed 41 staff and stakeholders. These included project managers/leads and staff involved in delivering PDS at the innovation sites, as well as local collaborators and partners. Further details of the participants are provided in the next chapters.

In line with the PBPP requirements, local leads identified the interviewees and sent an invitation to take part along with information about the evaluation. These interviews explored the activity that took place in the innovation site, the impact, strengths, weaknesses and sustainability of the activity, as well as issues around links with other services available for people living with dementia, staff training and the impact of COVID-19.

Case studies with people with dementia and carers

We undertook interviews with five people with dementia and nine carers to gather their experience of the service from the innovation sites. We used these discussions to create nine anonymised case studies.

Again, in line with the PBPP requirements, the local lead or PDS worker approached all potential service users to request their participation. Potential interviewees were provided with information about the evaluation and their role so they could give informed consent to take part or otherwise.

Individuals who were willing to take part either contacted Blake Stevenson directly, or innovation site staff sent their contact details, with their permission, to Blake Stevenson using encrypted email.

We also collected details about the support provided to individuals and the impact it had on them through interviews with the PDS worker in each area.

Postcard surveys with carers

In East Edinburgh and Shetland, we undertook a postcard survey of carers. The PDS workers in these areas distributed a postcard to carers along with information about the purpose of the survey. The postcard contained two open-ended questions:

- How have we helped to recognise and support you in your caring role?
- How has the support helped your partner/family member to live well with dementia and prepare for the future?

The postcard was pre-printed with a freepost return address so the carer could post the card back to Blake Stevenson at no cost. We received 50 responses from carers in East Edinburgh and eight in Shetland.

Online survey of GPs, health and/or social care staff

We designed an online survey for GPs, health and/or social work staff in each area. The questions were tailored to each innovation site and the activity taking place there but, in general, explored respondents' views of the site's work and its impact.

In East Edinburgh, the survey was distributed to eight GP practices with a request for one response from each, and we received four responses. In Nithsdale the same request was sent to three GP practices, all of which responded. In Shetland, the survey was distributed more widely to GPs, AHPs and social care staff and we received 16 responses.

Interviews with national stakeholders

Four national stakeholders in key strategic and policy roles from the Scottish Government and Health Improvement Scotland were interviewed to explore their views on the innovation sites' impact, strengths, weaknesses and sustainability of the models as well as the influence of sites on policy and practice.

Secondary data analysis

Every quarter, each site submitted data workbooks to HIS and these included a range of information about the service, including the number of people diagnosed with dementia, PDS uptake and diagnosis to PDS referral. This data was analysed by HIS to review trends and progress, and we undertook further analysis to inform this report. Nithsdale and Shetland submitted workbooks with data up to the end of March 2021, while Edinburgh's covered the period up to July 2021.

Phase 3: Analysis and reporting

We analysed the extensive qualitative data we gathered from the interviews and surveys in line with the overall evaluation questions and the outcomes identified in each site's evaluation framework. This involved a process of coding responses to identify key and recurring themes as well as any differences in viewpoints among different groups of participants or sites.

The quantitative data collected through the survey of health and social care professionals was collated and analysed using Snap Surveys software, while we analysed the data collected via the sites' data workbooks using Microsoft Excel.

We held several internal team meetings to discuss the key emerging themes before submitting a report outline to the Scottish Government and drafting this report on that basis.

Methodological challenges

There were some challenges which had an impact on our methodology and timescales.

COVID-19

The fieldwork took place during the COVID-19 pandemic so all the interviews took place remotely via telephone or web-based technology. This may have deterred some people with dementia and carers who would have preferred a face-to-face meeting from taking part in an interview.

While the PDS worker in East Edinburgh was able to continue delivering support throughout the COVID-19 pandemic, albeit using remote means of support instead of face-to-face contact, COVID-19 caused disruption to the delivery at the innovation sites in Nithsdale and Shetland.

In Nithsdale, no access to GP surgeries during the COVID-19 pandemic brought the testing at practice-based clinics to a halt in March 2020. Activity then focused on those patients who had already been referred to the clinic until the delivery of a new pathway began in May 2021. Furthermore, in recognition of the unprecedented demands facing primary care during the COVID-19 vaccine rollout, an online survey was prepared and the three practices who participated in the piloting of the new diagnostic pathway were invited to complete it.

Meanwhile, in Shetland, the PDS worker went on maternity leave at the beginning of the first national lockdown and, as a result of pressures related to COVID-19, there was no formal maternity cover. While some cover was provided by other staff in Shetland, this had an impact on the evaluation because there were 12 months when no services users were receiving support from the PDS worker. This reduced the pool of service users the PDS worker could approach to request participation in an interview with our team when fieldwork got underway on her return from maternity leave in February 2021.

Engaging interviewees

Engaging people with dementia in the evaluation was a challenge in all three areas but particularly in Nithsdale, where we interviewed only one patient diagnosed via the new pathway. Although this was lower than would be expected, it was important to acknowledge that much of the activity in Nithsdale was focused on one practice and therefore relatively small numbers of patients interacted with it. Furthermore, the interaction that took place was limited to a diagnosis made between April 2019 and March 2020. Both the limited contact with the project, and length of time between this contact and data collection, were significant barriers to patient engagement.

In addition, in Nithsdale, personnel changes meant that not all staff involved in each of the project models were available for interview.

Accessing PDS data

Another challenge was associated with data related to PDS in Edinburgh. The hope was to access data about the PDS delivered both by the PDS worker in the innovation site and the PDS delivered by the HSCP-funded Alzheimer Scotland Dementia Link Worker. This would have enabled a comparative analysis of key process and outputs. However, despite the efforts of the Scottish Government, Edinburgh HSCP, Public Health Scotland and Alzheimer Scotland, once there was clarity about data ownership, data governance requirements and the process for sharing the data, it was decided that it would not be possible to complete GDPR requirements and a data sharing agreement within the remaining timeframe for completion of the evaluation, so no comparison could be made.

PBPP approval

The process of obtaining approval from the Public Benefit and Privacy Panel (PBPP) posed a significant challenge for the evaluation. This was a lengthy and demanding process which was delayed by multiple factors.

In May 2019, the initial draft application was submitted to eDRIS (the team in Public Health Scotland that supports PBPP) and with feedback from the eDRIS team, a revised application was submitted in August 2019 for consideration by the panel.

Feedback from the PBPP highlighted that changes were needed:

- a clinical sponsor needed to be attached to the evaluation
- the data processor/controller relationship needed to be redefined
- new three-way data sharing agreements needed to be in place between our company, the Scottish Government and the three NHS Boards.

The process to revise the data processor/controller relationships and the associated paperwork, and to establish information sharing agreements between the Scottish Government and the health boards was lengthy due to the complexity of the process, and COVID-19 caused additional challenges and delays in finalising these documents.

Once the necessary agreements were in place, in July 2020 the revised application was submitted to PBPP. However, by this time, PBPP had to prioritise applications for research and evaluation related to COVID-19, and this further delayed a decision which was reached, and the application approved, in October 2020. We then confirmed approval from each individual health board involved and began fieldwork in December 2020.

In the next chapter, we explore the findings from the evaluation of the innovation site in Edinburgh.

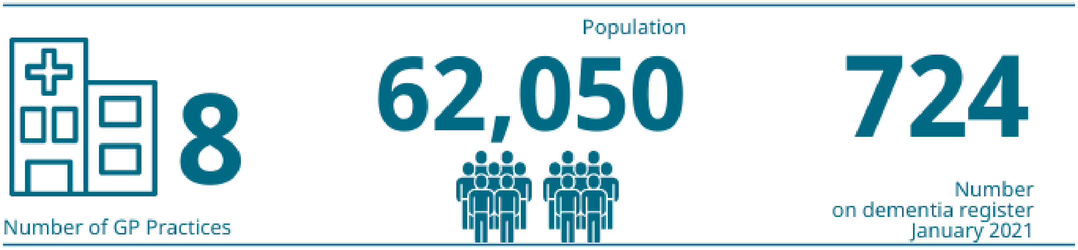
3. Findings: East Edinburgh

In this chapter we provide details of the delivery model and impact of the PDS innovation site in East Edinburgh.

Context

The East Edinburgh cluster was one of two GP clusters within the North East locality of the Edinburgh Health and Social Care Partnership. Based on 2019 data[6], the locality had a population of 118,760 and an estimated dementia population of 1,637. The East Edinburgh cluster has eight GP practices with 62,050 patients[7]. As of January 2021, there were 724 patients on the dementia register.

Figure 3.1 Profile of the East Edinburgh innovation site



Implementation

The innovation bid focused on delivering a service based in primary care that provided post-diagnostic support (PDS) for people with dementia and memory impairment living at home.

Their application to become an innovation site was jointly developed by the GP Cluster lead and the Strategic Planning and Commissioning Officer for Older People in the HSCP and they had a clear vision for the service. The bulk of the Dementia and Memory Support Service would test the role of a Dementia Support Facilitator based within the cluster who could deliver one-to-one support for people with dementia and their carers. It would also address the known gap of support for those with mild cognitive impairment (MCI) who often cannot access support without a dementia diagnosis.

The proposal included a part-time Project Manager to help design, develop and co-ordinate the service. Having just completed a 12 month pilot at another Edinburgh GP practice supporting people with dementia, and with previous experience in dementia and health and social care project management, she was able to add to

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[6] https://www.edinburghhsc.scot/the-ijb/jsna/dementia/

[7] Public Health Scotland, GP Practice Contact Details and List Sizes, July 2021: https://www.opendata.nhs.scot/dataset/gp-practice-contact-details-and-list-sizes

the vision. She introduced the idea of delivering group work sessions and would manage a full time Band 4 Dementia Support Facilitator (DSF).

The implementation of the project was aided by the support of the Focus on Dementia Team who helped refine the approach and co-develop the driver diagrams to reinforce the clarity of what the project aimed to do and a needs assessment was carried to inform the service design and ample time was spent developing the service specification and the associated systems and role descriptions.

Once the postholders were appointed, a lengthy process due to the NHS Lothian recruitment procedures, work to create the infrastructure for the service began. There were several elements to this:

- establishing the paper-based systems and processes for the service – awareness-raising materials, documents like referral forms, introductory letters, support plans and records
- raising awareness across the cluster, and with relevant local stakeholders, about the new service and more generally about dementia – through information sessions, leaflets, meetings at all eight GP practices, dementia awareness training
- adapting the IT system so that the DSF could access the relevant patient records across all eight sites. This involved work with the cluster's IT Manager to set the DSF up to access individual practice systems with passwords and usernames and the DSF had to learn to use VISION and EMIS software. The IT Manager created guidelines and a report inside VISION so that the DSF could access data and print reports regardless of where she was located.

Management and governance of the Dementia and Memory Support Service

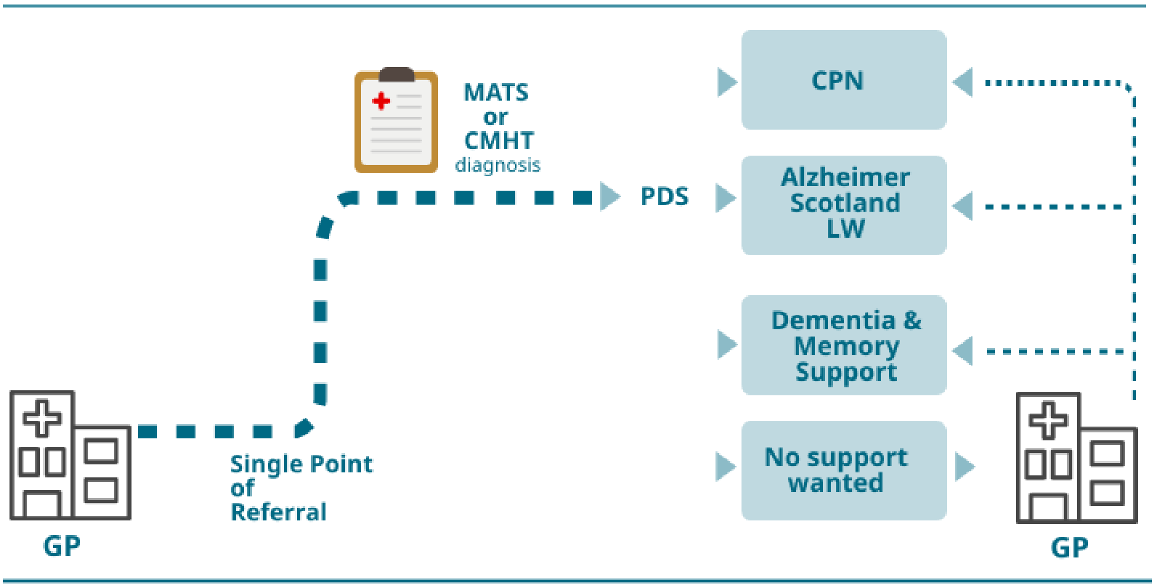
The Project Steering Group played a key role in guiding and supporting the new service and overseeing the Project Manager, whose role was key in communicating with stakeholders, developing processes and systems (which met the PDS Quality Improvement Framework) and line managing the DSF. The Project Manager also led the PDS group work and delivered and/or co-ordinated the dementia awareness training in the GP Practices.

Delivery

Before the new service was established, PDS in Edinburgh was predominantly delivered by Alzheimer Scotland Post Diagnostic Support Link Workers (funded through a contract by the Edinburgh HSCP), Older People's Community Mental Health Teams (CMHT) and the Memory Assessment and Treatment Service. The service offered by Alzheimer Scotland was intended for people who are at the earlier stages of their dementia journey – those people newly diagnosed and with the ability to engage and potentially develop some self management skills to continue to live well with dementia following PDS input.

With the new service and the DSF role, people newly diagnosed with dementia, regardless of the stage of the illness, and those with MCI, could access support in the East Edinburgh cluster.

Figure 3.2. East Edinburgh diagnostic pathway



The role of the Dementia Support Facilitator

The full time DSF provided support across the cluster. As of June 2021, the caseload was 60 people with dementia and ten people with MCI – higher than normal because it was more difficult to discharge people due to the impact of COVID-19.

People access the Memory and Dementia Support Service via several routes. This can be through the GP and primary care staff in the practice, the CMHT or MATS. However, as well as the referrals, every eight weeks the DSF works through the GP’s lists of people newly diagnosed with dementia, so that people are picked up early and no one was overlooked. This was the main source of access to the service.

The Memory and Dementia Support Service had 613 potential referrals since it began, at a rate of around 180 per year since 2018, a number that seems unaffected by COVID-19. Of the potential referrals:

- 456 (74%) were identified from the GP lists
- 99 (16%) were GP referrals
- 49 (8.0%) were from MATS/CMHT
- 9 (2%) were from other sources.

The process for making contact with someone who had been identified from the GP list as diagnosed with dementia involved sending an introductory letter and leaflet about the service and then following up with a telephone call. If the person was directly referred in, e.g. by the GP, the first introduction was by telephone.

Of the 613 potential referrals, 304 were elibible for support. The others were already receiving support from an Alzheimer Scotland Link Worker, CMHT or MATS or were in hospital or a care home. Of the 304, 286 started PDS, which means 94% took up the offer of PDS.

Once someone agreed to start PDS, the DSF made arrangments for their first meeting and to spend time getting to know the person with dementia and, where relevant, their carer or family member.

Averaged across 2018 to 2020, the time from referral to first meaningful contact was 55 days. However, this fell sharply in 2021 to 16 days (from a high of 67 days in 2019).

This average reflected the fact that although identifying people promptly from GP lists, the DSF usually had to wait several weeks/months until MATS or CMHT input was complete around diagnosis.This improved through work in forging links between the different services – the DSF with individual workers and the Project Manager at management level – and, most importantly, the attendance of the DSF at weekly allocation meetings held by CMHT.

Table 3.1: Average days from referral to first meaningful contact - PDS

Practice name	2018	2019	2020	2021	2018-21
Craigmillar Medical Group	17	84	73	40	44
Durham Road Medical Group	53	158	87	14	78
Milton Surgery	177	81	44	3	74
Niddrie Medical Practice	284	33	0	7	60
Portobello/Conan Doyle	37	48	59	15	42
Southfield Medical Practice	60	53	46	0	52
St Triduana's Medical Practice	20	49	47	23	39
The Baronscourt Medical Partnership	43	86	114	14	75
Average days	**48**	**67**	**63**	**16**	**55**

In contrast, support for people with MCI was provided very quickly as the DSF did not have to wait for MATS or CMHT to complete their input. In the period from 2018-2021 there were a total of 81 referrals to the MCI service. Numbers peaked at 31 in 2019 and fell slightly in 2020 before increasing in the first half of 2021.

All of these referrals are identified from the GPs and once contacted 76 (94%) accessed support. The average time from referral to first meaningful contact fell from 17 days in 2019 to three days in 2021.

Table 3.2: Average days from referral to first meaningful contact - MCI

Practice name	2018	2019	2020	2021	2018-21
Craigmillar Medical Group	10	33	2	6	13
Durham Road Medical Group	-	4	8	2	4
Milton Surgery	3	8	-	2	6
Niddrie Medical Practice	-	-	-	4	4
Portobello/Conan Doyle	22	9	4	2	8
Southfield Medical Practice	7	1	1	1	3
St Triduana's Medical Practice	11	59	1	4	19
The Baronscourt Medical Partnership	23	7	1	-	8
Average days	**14**	**17**	**3**	**3**	**10**

Working with general practice staff

As part of the awareness-raising across the cluster and to help secure engagement, training was delivered to general practice staff in the early stages of the service. This included:

- dementia training at the *Informed level* with eight staff (healthcare assistants, receptonists, practice managers and a Practice Nurse)
- dementia training at the *Enhanced level* with a GP
- three training sessions on *Adults with Incapacity* with GPs (with the support of HIS).

In addition, the Project Manager supported practices to become more dementia friendly by auditing their buildings. This meant that when opportunities to refurbish or refresh areas arose the physical environment could be adjusted.

All practices referred patients to the Memory and Dementia Support Service, which had a high profile across the cluster. At each practice the Quality Leads and Practice Managers were the key contacts, helping to circulate information about the service and dementia related materials. They also liaised with the DSF about room availability and ensured she had space to work on the dates she was based in their practice.

Before the COVID-19 pandemic the DSF (and when relevant the Project Manager) attended cluster meetings and practice meetings to discuss patient care for those newly diagnosed and the service she provided. This helped staff to understand the role of the DSF and how their care could enhance this. It also gave them the opportunity to get to know the DSF.

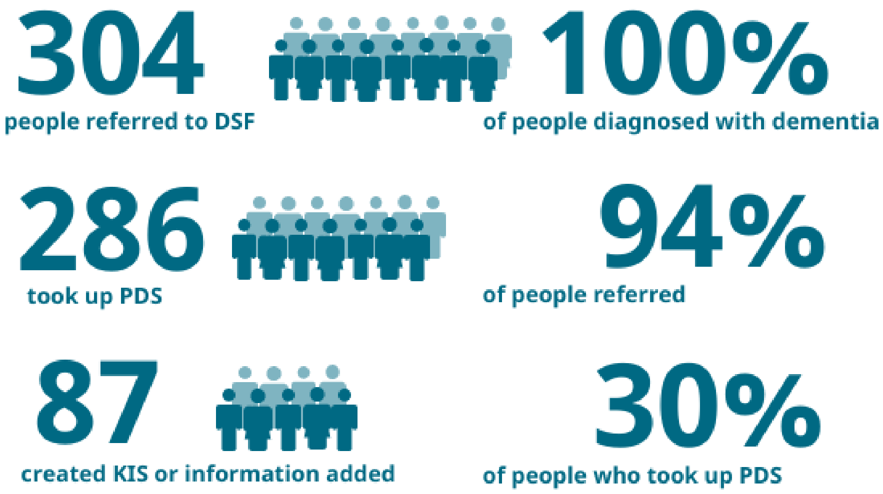
When the DSF was based in the practices, there were also informal opportunities to speak to practice staff as well as formal discussions with GPs about patients in regard to changes in behaviour, circumstances or other complex issues that required a medical intervention.

Outwith particular concerns the DSF had regular communication about progress with PDS including all relevant information on GP notes and, for many, adding information to the Key Information Summary (KIS). The DSF was able to create or update the KIS independently rather than passing on information for the GP to input, which helped streamline the process, increase KIS uptake and save GP time.

For those that have been supported:

- 40 had a KIS created
- 47 had information added like background and home issues, future planning arrangements, power of attorney details and current functioning abilities.

Figure 3.3: Summary of PDS activities (please note the 100% refers to the people known to be newly diagnosed on the East Edinburgh GP lists).



Working with others

To ensure a joined up approach, the DSF linked up with others who provide support to people with dementia. As well as working closely with the primary care staff in all eight practices, the DSF developed effective working relationships with the Alzheimer Scotland Link Worker, the staff at MATS and the CMHT.

The DSF attended the weekly allocation meetings that involved the Old Age Psychiatrist, the CPNs, OTs, psychotherapists and the Older People's Teams. At these meetings individuals are discussed, triaged, and allocated to a team/individual. Not only did the DSF contribute to the discussions, ask questions and understand next steps for individuals, she also took on the appropriate PDS cases and built a good working relationship with the other teams. Outwith these meetings the DSF was in regular contact with MATS and CHMT to check the status of those they were assessing or supporting.

The DSF worked very closely with the Alzheimer Scotland Link Worker, collaborating to ensure they were complementing the PDS they each provide. They checked they were not working with the same individuals and provided peer and professional support and encouragement to each other.

One-to-one support

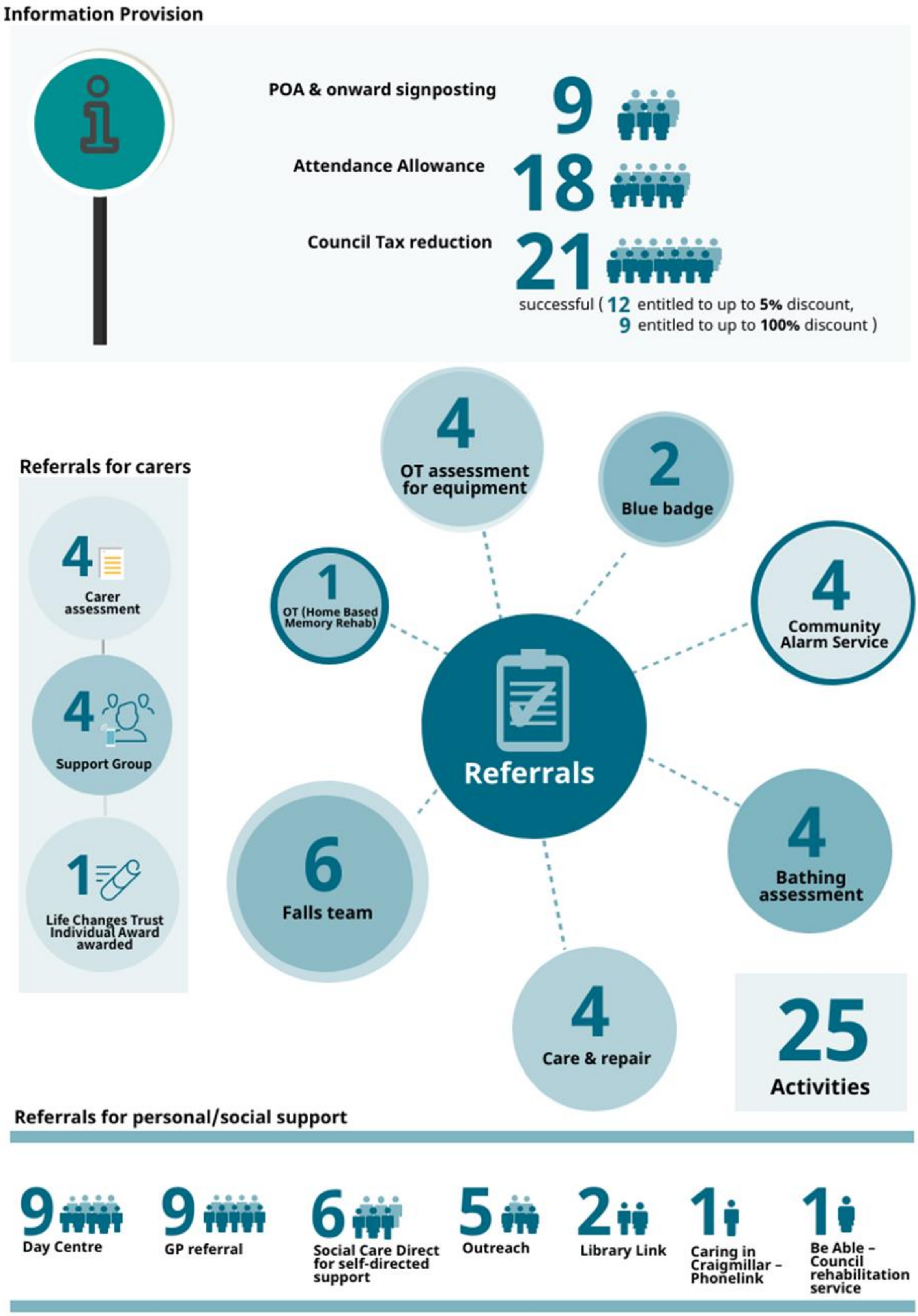
The majority of support was with individuals. The 5 Pillars Model provided the framework for working with people with dementia, their families and carers. It helped in developing a personal plan around an individual's own support network, new community connections, and tools and resources, supporting them to live well and independently with dementia for as long as possible.

Before the COVID-19 pandemic, the DSF delivered most of this support at home, although there was the option to be seen in practice. From March 2020, the DSF provided one-to-one support by telephone, email and Near Me, and posted or emailed additional information. As restrictions eased, the DSF made home visits in the garden, when this was appropriate (and with access to PPE).

For all cases, at the end of support, concise plans were produced which included the *Getting to Know Me* document and the *Anticipatory Care Plan*. Of the 286 people supported, 72 had personal plans transferred to GP systems on discharge. An A4 summary was completed, scanned and recorded on VISION/EMIS and, where relevant, also transferred to the KIS. An evaluation form was sent to gather feedback and inform service delivery and 54 forms were completed and received.

Figure 8 overleaf summarises information from a sample of 30 cases over an 18 month period and higlights the variety and volume of support from the DSF.

Figure 3.4: Variety and volume of PDS from East Edinburgh DSF



MCI

For people with MCI the DSF provided support and reassurance by talking to them about their anxieties about their impairement and explaining what help they could access and, if referred for a diagnosis, what that process involved. The support could also involve putting in place practical things whilst waiting for their dementia assessment.

At the time of writing this report, just over 40% (33) of people supported with MCI later received a dementia diagnosis. The support provided by the DSF in the early stages helped to establish and then build a relationship with those individuals that then continued once they had a diagnosis.

Group work

The service also offered group work for people with dementia and their carers. The PDS groups were delivered to the same participants over five weeks and five groups took place pre-COVID-19.

The purpose of the groupwork was to provide the opportunity for people affected by dementia and memory problems to meet others in a relaxed, supportive and informative setting. The groups were small, usually five to ten people and led by a different professional guest each week - the Project Manager, a Community Mental Health Nurse, an Occupational Therapist, a third sector organisation and the Alzheimer Scotland Link Worker.

Each session started with a themed presentation which then led to open discussion.Typically the five weeks were themed as follows:

- understanding dementia, including medication
- building and developing skills, the value of routines, memory maintenance and enabling environments
- living well with dementia, keeping physically & mentally well
- planning for the future
- keeping connected, including support for carers.

Online group work

An online version of the group work programme was developed during the COVID-19 pandemic. The approach was different and delivered in partnership with a third sector organisation to allow more freedom with the use of technology. The focus was on peer support, as this was what participants requested.

The programme aimed to create a small online group where people came together to talk about their current experiences in restricted times and learn from each other about what was helping. Each week was structured around an activity and different professionals were also involved in some of the sessions to share their expertise. By delivering the online group in collaboration with Pilmeny Development Project the sessions could take place on Zoom, a platform that more people were comfortable using.

Between six and eight carers and/or people with dementia engaged each week with the online group work programme.

Evaluating the East Edinburgh site

As described in chapter 2, meetings with the staff and steering group members alongside review of documentation (like the driver diagrams and project outcomes) informed the evaluation plan for the project. A series of outcomes were identified and agreed that reflected local activity. East Edinburgh wanted to:

- increase PDS uptake
- ensure people with dementia and their carers have an improved experience of PDS
- give primary care staff improved confidence in supporting people with dementia
- reduce the need for GPs to support people with dementia and their carers
- look at opportunities to develop additional areas of activity that benefit people with dementia and their carers e.g., increased group work, more dementia friendly practices, PDS in care homes test of change, ACPs and KIS uptake.

To gather the evidence for the evaluation of the innovation site, interviews were conducted with project staff, GPs and practice staff, local stakeholders and service users. This was complemented by analysis of the workbook data, carers postcards and a GP survey. Their responses and the data collated inform the next section, which describes the impact of this innovation site.

Table 3.3 summarises the breakdown of the contributors and table 3.4 provides the details of the local staff and stakeholders.

Table 3.3: Evaluation participants in East Edinburgh

Project staff/steering group	Local partners /collaborators	People with dementia	Carers	Carer postcard responses	GP survey responses
6	16	3	5	50	4

Table 3.4: Details of the local staff and partners

Project managers/staff/steering group	Local partners/collaborators
Project Manager Former Dementia Support Facilitator (DSF) and current DSF Steering Group members – GP Cluster Lead, NE Cluster Manager NHS Lothian, Strategic Planning and Commissioning Officer – Older People, Edinburgh HSCP	GPs x 2 Practice Managers x 3 GP Link worker Alzheimer Scotland Link Worker Health Development Officer, Edinburgh Leisure Project Manager, Pilmeny Development Project IT cluster support Old Age Psychiatrist MATS team x 3 CPN, CMHT OT, CMHT

Project managers/staff/steering group	Local partners/collaborators
	Improvement Advisor – HIS[8]

Impact of the service

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 section explores how the work of the innovation site has impacted on PDS uptake, people's experiences of PDS, and how the work of the service has affected GPs and practice staff.

Increased PDS uptake

The most up to date figures for PDS in Scotland showed that 8,021 people diagnosed with dementia were referred for PDS in 2018/19. This represented 43% of the estimated incidence of dementia for that year. At an NHS Lothian level, the percentage of estimated incidence was 34%.

In the East Edinburgh innovation pilot, the process of checking the GP lists meant that everyone who received a dementia diagnosis, and was appropriate to contact, was considered for the service. These regular trawls yielded many people who had not been referred to the Dementia and Memory Support Service by the GP. Putting this system in place meant that an additional 134 people were identified who then went on to receive PDS. A process in place that identified everyone on GP lists recently diagnosed with dementia ensured that PDS was made more widely accessible [9].

Table 3.5: PDS referrals in East Edinburgh

Year diagnosed	GP list reviewed and then went on to start PDS	Referrals from GPs/MATS/CMHT who started PDS
2017/18	35	11
2018/19	23	40
2019/20	49	42
2020/21	27	40

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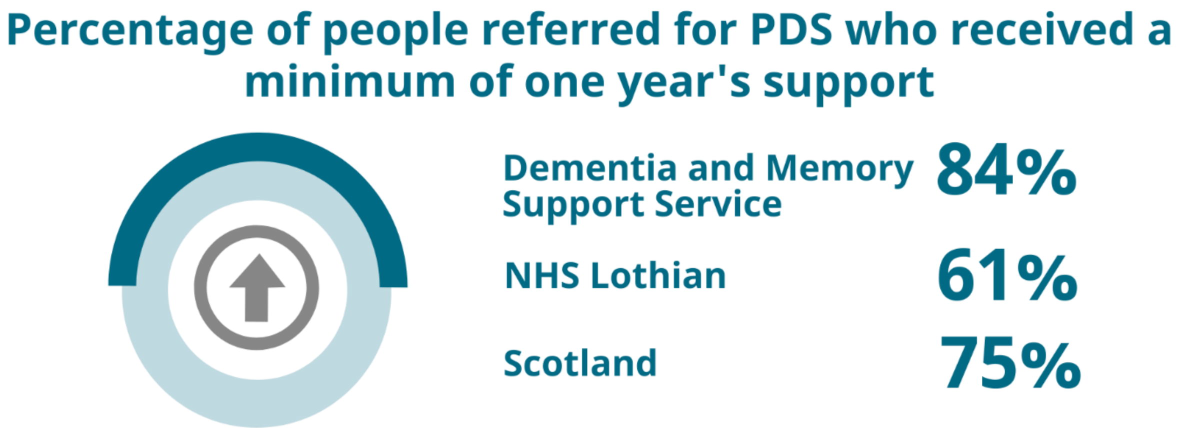
[8] This interviewee was not included in the numbers in Table 3.1 because she was interviewed twice as the Improvement Advisor and as a national stakeholder.

[9] Further comparative work may be beneficial to compare with local PDS LDP returns to identify if there has also been other PDS input from other Edinburgh PDS services recorded across the Edinburgh PDS pathway.

A process in place identified everyone recently diagnosed with dementia known to GPs, and ensured 100% were offered PDS.

National data shows that 75% of people who received PDS did so for a minimum of one year. The equivalent figure in NHS Lothian was 61% for the same period. For the East Edinburch Dementia and Memory Support Service the figure was 84% (based on the workbook data[10]). This, again, compared favourably with the Scottish and NHS Lothian average.

Figure 3.6: Comparison of local and national PDS support rates – those that received at least a year's support



Improved experience of PDS

There are several elements where the Dementia and Memory Support Service helped to improve the experience of the PDS for people with dementia and their carers to enable them to live well and independently for as long as possible.

Support to people with a dementia diagnosis

The bespoke service took many forms in response to the individual circumstances and needs across each pillar of support. The service supported people in different ways including:

- **understanding the illness and managing the symptoms**
  As well as working with individuals and family members to help make sense of what was happening, how symptoms manifested and behaviour changed, the DSF shared information guides and leaflets to reinforce understanding and practical guides to help self-manage and make changes to continue to live at home safely and independently

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[10] There were 130 people who accepted PDS and were discharged between 2018 and 2021. They were discharged for reasons other than death, becoming significantly unwell, moving out of the area, or moving into a care home. Of these 130, 109 (83.8%) were discharged in their 12th month of support or later

- **peer support**
  As well as access to a group work programme, those supported were linked by the DSF to local dementia/carer specific activities. These groups brought together people with dementia and their families and carers in an informal environment where they could get information from professionals and meet other people in similar situations. The opportunity to do this was offered by many organisations, which included Dementia Dogs, Edinburgh Leisure, Capital Theatres, Movement for Memories, Pilmeny Development Project, Sporting Memories and Voice of Carers Across Lothian (VOCAL).
- **supporting community connections**
  The DSF worked with the individual and family to understand their interests and the existing support that could be built upon. She established good working relationships with organisations that supported the needs and interests of those she was working with and helped to widen their local network with referrals and suggestions
- **planning for future decision making**
  The DSF explored sensitive areas such as advance directives so that the wishes of the person with dementia were captured while still able to make their own choices. She also provided information for power of attorney (POA) and onward signposting to put that in place
- **planning for future care**
  Under this pillar the DSF worked with the person with dementia to develop a personal plan which captured their choices and future wishes. She also liaised with the relevant teams that could assist/make assessments for personal or social care, like enablement equipment, care packages, attendance allowances and council tax reductions.

The approach, manner and experience of the DSF was welcomed by those accessing the service and organisations that she worked with. She was able to reminisce with them about the city, could empathise with their home situations and listened to their wishes which were then captured in a plan. The DSF liaised with other professionals on their behalf, from discussions with the GP about appropriate support, to advocating for the need for practical aids with the Falls Team.

> *"DSF made suggestions which we took on board, from digital clocks, white boards, menu chart, labelling rooms, drawers etc."* Carer

The project evaluation forms received from people with dementia mentioned how they liked the PDS being local and based within their GP practice. Another frequent comment was on wanting the service to go beyond one year.

Crucially, during COVID-19, as a discrete service for the cluster service staff were not redeployed to front line duties. The DSF was able to continue to work remotely and support people, recording interactions and updating GPs.

> *"During COVID I used the DSF more and found her extremely flexible about how she supported the patients."* GP

Support to carers

Many carers were more aware about what was available and how to access it as a result of the service. They also felt more supported than before because of the regular contact with the DSF. The carers postcard responses showed that the work of the DSF:

- provided specific advice and support to improve practical changes at home

  "We benefitted from getting access to physical aids and financial help that maximised his ability to stay at home."

- improved their understanding and ability to fulfil their caring role

  "The support has helped me to establish a daily routine for my husband that is beneficial to his wellbeing and has taught me how I can address any problems that may arise with his care in the future"

- signposted them to relevant services

  "Given me links and ideas to improve quality of life and helped me a lot with useful information and contact numbers for just now and the future."

- gave essential emotional support and reassurance.

  "Listened to my concerns as a carer and, provided accessible support when required to improve my wellbeing, general health and independence."

The group work was highlighted as a unique example of effective support for both the carer and person with dementia.

> *"I don't know of any other group where the person with dementia and carer get structured peer support where you have discussions on certain topics, and you learn something as well as the social benefits."* Local organisation

The carers acknowledged the important role of the group work in making connections with others in similar situations and providing practical support in an informal and supportive environment.

> *"The group meetings that the DSF organised with carers and people with dementia helped me in understanding the issues involved in caring and helped in not feeling isolated."* Carer

Not only was the community based service bespoke, but the time between referral and active support meant that there were not lengthy delays. Practical changes and support happened in a timely fashion so that the person with dementia and their carer could benefit from them whilst still living at home.

> *"DSF arranged visits from different agencies to access and provide tools which allow him to stay in his own home."* Family member

Outside of the home, the experience of PDS was likely to be further enhanced in by attending a practice that was more dementia friendly or having an appointment with a GP who had a greater awareness of dementia. The dementia awareness training gave practice staff a better understanding of the needs of people with dementia and the regular updates from the DSF and additions to the patient notes meant the GPs were more aware of the home situation.

> *"I was aware of the existence of the Alzheimer Scotland Link Worker and PDS but that was the extent of it. I couldn't have given you any examples of which patients were being supported and no recollection of specific feedback unlike the*

> *DSF who will make suggestions as to who to involve and ask district nurses to visit or ask me about specifics."* GP

Strengthening links and knowledge amongst other services

As well as working directly with others for individual cases, the DSF built effective working relationships with other organisations and teams, and built links between them which helped to join up services and activities that benefitted people with dementia and their carers.

> *"The DSF helped us to build relationships with individuals from other organisations through planning meetings…built knowledge of services available and this helps us to help service users."* Local organisation

They have also helped other organisations to develop their services.

> *"Feedback from the DSF has helped us to create different activities for people with dementia, e.g., walking groups, and the DSF has shared materials about our services with people with dementia and carers. It is a good partnership…we are getting appropriate referrals and it is good to see referrals from primary care to community sport."* Local organisation

With support from the DSF some people with MCI felt confident to go forward for a diagnosis. Others waiting for their assessment appointment were reassured by the DSF's advice about the process and what that would entail. The GPs recognised that the support for those with MCI addressed an unmet need during a worrying pre-diagnosis period, replacing regular GP appointments at a time when there was limited medical support that could be given.

DAVID'S STORY

David was diagnosed with Alzheimer's in his sixties. He lives with his wife Marie.

Before diagnosis he was an active person, but stopped some of the activities he enjoyed when he knew he had Alzheimer's. He also developed some sensory challenges, including an aversion to bright lights and loud noises. This made it difficult to spend time with his young grandchildren, and he missed seeing them.

David found it hard to come to terms with his diagnosis and the limitations it placed on his life. He was keen to meet others with the same diagnosis.

CASE STUDY
EDINBURGH

CARER SUPPORT

- The DSF signposted David and Marie to VOCAL for information on benefits and carer's support.

PEER SUPPORT

- The DSF referred David to Movement for Memories, which helped him re-engage with exercise through the gym and swimming.
- David also attended the DSFs group programme.

PLANNING AHEAD

- The DSF provided the couple with information about a Council Tax reduction and the Blue Badge scheme.
- The DSF helped the couple make plans for David's future care and put in place emergency care back ups should anything happen to Marie, including an advance directive.

LIVING WITH DEMENTIA

- The DSF liaised with the GP to get David counselling about his diagnosis.
- The DSF encouraged the couple to visit the Smart House and find out more about technological aids to help live with dementia.
- She also helped David deal with sensory issues so he could spend time with his grandchildren and helped him get back to cycling.

> "My diagnosis made us feel the rug had been pulled from under our feet but the DSF helped with the initial shock of things and gave us hope that dementia is not the end of the world."
>
> DAVID

> "The support of the DSF has helped us plan ahead and taken away the fear about what the future might hold."
>
> MARIE

Increased knowledge and awareness amongst GP practice staff

In the early stages of the service dementia, awareness training was delivered to practice staff and training on *Adults with Incapacity* was delivered to GPs. The practices in the cluster also receive regular communications from the Project Manager on the developments and services for dementia care and support and signposting to relevant and current information.

With support from the Project Manager, some practices that were remodelling or refreshing their building took the opportunity to make the environment more dementia friendly. This improved the physical environment and sensory experience of attending a GP practice.

This formal training and regular information sharing increased the knowledge and skills around dementia care and support and the informal awareness-raising and the DSF's presence in the GP Practices raised the profile of dementia care and influenced GPs' actions.

As well as the increased awareness and knowledge, GPs had an improved understanding of the support being provided to the person with dementia and, where relevant, their carer. This not only helped them to provide relevant support during their interactions with their patients but it was reassuring to know that the DSF was actively supporting them as well.

> *"We are increasingly busy with other patients, and we can now rely on the PDS team, who provide excellent support for patients, so that I don't worry that they are slipping through the cracks."* GP

Greater efficiencies

The Dementia and Memory Support Service complemented the work of the GPs. An IT cluster Manager analysed the impact of the service on GP appointments, finding no impact on number of appointments but a reduction in their length. This was possibly because the support from the DSF allowed the GPs to focus on their medical issues rather than the social, emotional and practical concerns associated with dementia.

> *"I can see in the notes that [our DSF] is supporting a patient and I am hugely reassured that I can focus on the medical problems!"* GP

More information was needed to understand the extent to which the service had offset some of the GP workload but even without the evidence from the appointment data, the GPs felt that the frequency of visits from '*frequent attenders'* lessened when they were being supported by the DSF.

RICHARD'S STORY

Richard was diagnosed with Alzheimer's in his late eighties. He lives with his wife Ann, who also has health issues, and their adult son.

At the time of the DSF's first meeting with Richard, he was housebound, frail, and dealing with incontinence and severe osteoarthritis, which affected his mobility.

CASE STUDY
EDINBURGH

CARER SUPPORT

- The DSF helped Richard and Ann with a social work referral and they now receive care at home three days a week, including help with showering.

PEER SUPPORT

- Richard is interested in music and used to play several instruments. The DSF helped him join a singing group at his local church.
- The DSF also referred Richard to day centres for support.

PLANNING AHEAD

- The couple established POA and the DSF added information to the KIS about date of diagnosis.
- She also helped Richard and Ann secure a higher rate Attendance Allowance and Council Tax reduction.

LIVING WITH DEMENTIA

- A referral to OT led to a variety of equipment such as grab rails, commode and raised toilet seat being installed in the house to help Richard live safely.
- The DSF referred Richard to the Bladder and Bowel service to help with continence.

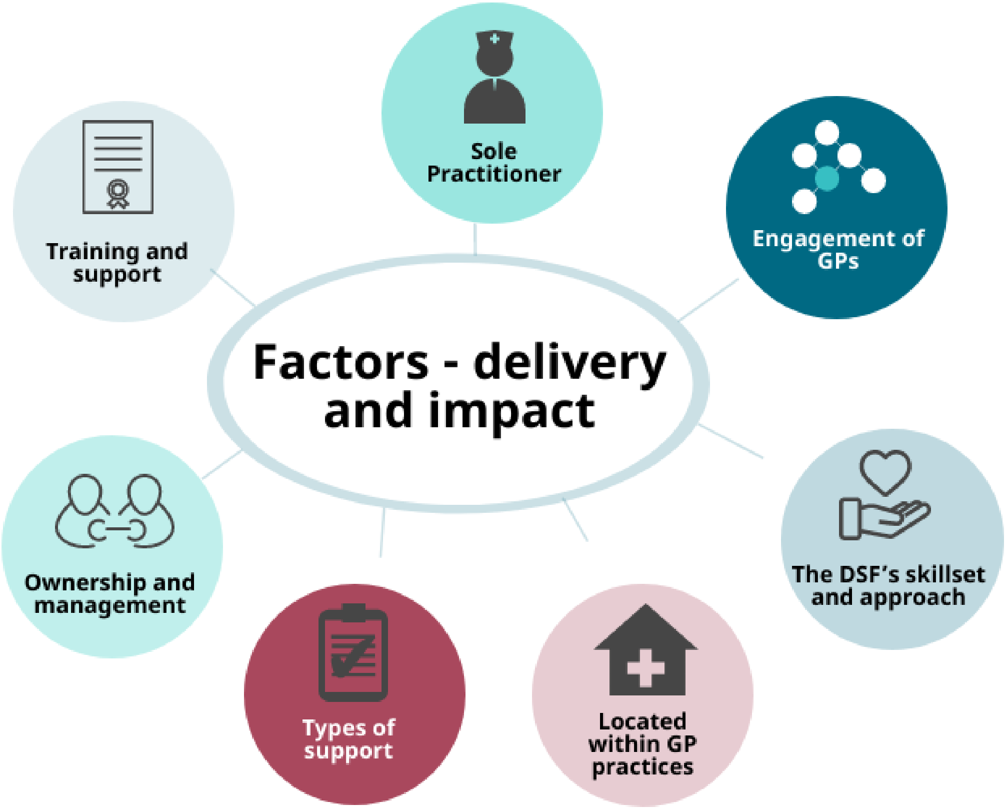
"...you need that extra support...She opened doors to what's available in the community...we wouldn't have known what services and activities were around otherwise."
ANN

"The help of our DSF means I'm better able to cope. It's made living with dementia that much easier. She helped Richard to flourish and live a better life. "
ANN

Learning, enablers, and barriers

In this section, we consider the learning from this innovation site and discuss the enablers and barriers to its successful implementation and delivery. There were a number of factors, summarised in the diagram, that influenced the GP cluster's engagement, awareness and delivery of the service.

Figure 3.7: East Edinburgh – factors affecting delivery and impact



Sole practitioner

The DSF was not part of a specific team within the cluster and so cannot benefit from being part of a larger network of support, whether liaising with peers or accessing training. Although line managed by the part-time Project Manager, and a self-motivated person, it made for a solitary role, particularly during lockdown, and it also meant that the casework was untouched when she was on annual leave or if she had been off sick.

Relying on one person to deliver the bulk of the service and the isolation of the role made this a fragile approach. Any future roll out should explore how this role could be attached more closely to a team of linked workers, e.g. in a practice or hosted within a third sector organisation.

Engagement of GPs

The GPs in the cluster were very engaged and aware of the service. The Cluster Quality lead was a

> *"pivotal advocate for the project and getting the other practices on board."*

He was also instrumental in promoting the focus on MCI, while his strong clinical leadership and like-minded colleagues meant a cohesive group of practices that fully embraced the services.

This was critical for establishing the DSF role and maintaining the high profile of the service. In contrast, the other GP cluster in NE Locality was not open to extending the service across their practices. This highlights one of the challenges of working with GPs: if there was not an enthusiastic partner who can champion the cause and engage colleagues, new services may not be embraced and expanded.

The DSF's skillset and approach

The DSF was well respected in her role and possessed the experience and skills to provide an effective service despite the level at which the role was filled. As well as providing the 1:1 PDS support and reassurance for MCI clients, she also built effective working relationships with the teams in secondary care and the team within the third sector. At times she had very complex cases and the grading of a Band 5 would have better reflected her role and responsibilities as a sole practitioner.

Located within the practices

The scope to be based in the practices provided a wide range of opportunities to develop relationships, facilitate learning and increase understanding with primary care staff. With access to the patient records and the dementia register, the DSF gained insight into those she was supporting and identified those that she could support. The link to the practice meant that her role and the service was almost instantly accepted and the existing trustinig relationships built between patients and GPs made people more responsive and the conversations easier. The very local knowledge about services and support helped to provide a more bespoke PDS and the regular liaison with the GP or Practice staff, updating of patient notes and KIS ensured that a medical and social/emotional/practical response was part of the PDS offer.

Types of support

Alongside the traditional 5 Pillars Model approach to PDS, the service also supported those with MCI. Many recognised the value of the MCI support and the likelihood that those being supported might seek a diagnosis earlier and then, if diagnosed, start PDS in a timely fashion.

> *"The DSF is filling a gap with supporting MCI, it's so important to take support as early as possible and with MCI clients the work can start pre-diagnosis."*

The group work programme also provided another dimension to PDS, with the rare opportunity to provide support to the carer and person with dementia in an environment with their peers. The carers in particular found this programme helpful for making contacts within the community, sharing their experiences and hearing from the experts.

Crucially, in this innovation site, PDS continued remotely during the COVID-19 pandemic. The nature of the team meant that the DSF was not redeployed to front line services and she quickly learned and embraced new technology, like Near Me. She also kept in regular contact by phone and, when able, conducted garden visits to continue to provide much needed support during lockdown. The group work programme also moved online, in partnership with the third sector so that it could be delivered via Zoom.

Ownership and management

From the outset, the innovation site had a clear vision about the service that they wanted to provide. There was a steering group, with two of the authors of the bid and the relevant decision-makers then overseeing the service. Each element was well thought through and that focus remained throughout the project.

The commitment to the service was evident and included an annual financial contribution from the cluster. The service was planned and resourced, including the Project Manager role, to ensure that the appropriate systems and processes were in place. This included addressing IT challenges and thus enabling the DSF to access patient records from anywhere in the cluster, and ultimately, from home.

As was often the case in primary and secondary care, space within buildings was limited. There were challenges in identifying rooms within practices as a base for the DSF and to provide training and group work space. However, regular liasion with Practice Managers overcame most of these issues. The support and associated paperwork, plans, KIS and monitoring information was shared between the DSF and the Project Manager. Some element of administrative support could have alleviated these tasks and enabled more information of the quality of support to be captured.

Training and support

The support from the Focus on Dementia team was particularly helpful in establishing the service, using driver diagrams, PDSA processes, measurements plans, and throughout the programme with Quality Improvement teaching, data collection, reporting, peer support sessions and monthly 1:1s. The Steering Group members and the Project Manager highlighted the value and importance of such support to help navigate the challenges of an innovative approach and, with the service sitting outside other services, supporting the Project Manager in her role. They appreciated the training that was delivered to the GPs by the Consultant Psychiatrist and the advice around dementia training for the DSFs.

Sustainability and spread

The East Edinburgh innovation site received extended funding from the Scottish Government to deliver the Dementia and Memory Service until March 2022 and it was hoped that during this extension period a sustainable funding model can be identified for the service.

The hope was that the service can be extended to another Edinburgh GP cluster and this was being proactively explored . The existing service was also hoping to explore how PDS could be delivered from primary care to people newly diagnosed in care homes.

However, this was a piecemeal approach. There are opportunities to join up partnerships and services based in GP practices, like the national GP community link worker programme that could be better exploited. Although there was evidence that the service reduced the impact on GPs, the value of the service required a rethink for PDS funding streams and primary care planning and commissioning so that the strengths and qualities of this PDS provision can be experienced by more service users.

Summary

The East Edinburgh innovation site has shown how a peripatetic worker based in the GP Practices with a good working relationship with primary care staff and access to GP systems and clinical records can provide a bespoke PDS service for patients in the cluster.

With high engagement from the GPs in the cluster and robust management and governance arrangements, the service has developed into a key service in this part of the City. Strong working relationships with others providing support in primary and secondary care and effective links with the third sector further enhance the service. Supporting people with MCI has been a welcomed addition, filling a gap in provision and providing reassurance and practical assistance ahead of a diagnosis.

The work of the Dementia and Memory Service has led to:

- **Increased PDS uptake** –when offered PDS endorsed by their own GP, engagement and take up of the Dementia and Memory Service was high.
- **People with dementia/carers with an improved experience of PDS** – from the one-to-one support to the group work, the DSF has raised their awareness of what support was available, helped them to understand what was happening and connected them to others in a similar situation. Alongside the emotional support from the DSF, they were given practical support about changes that they might need to make in the home, advice about future care and what and help to access financial assistance and resources.
- **Primary care staff have improved confidence in supporting people with dementia** - the DSF’s close working with primary care staff and training opportunities has 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 at most of the practices meant she was on hand for GPs and practice staff for advice.
- **Reduced need for GP support among people with dementia and carers** – the anecdotal evidence showed that the DSF alleviated the social, emotional, or practical support that GPs often need to address during appointments, leaving them free to focus on medical issues. The GPs had a good understanding (from viewing the patients’ notes) of how the DSF was

supporting 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 has improved the connections and transitions for people with dementia and their carers whether with MATS or third sector organisations. The unique offer of group work both face-to-face and virtually has widened engagement and support for carers and people with dementia and the potential extension of the service to another cluster and the possible work in care homes means that the service was branching out and could have an even wider impact.

The challenge now for the innovation site was to secure funding to embed the DSF role within primary care and consider how it can link in with other programmes so that it becomes part of a wider sustainable service.

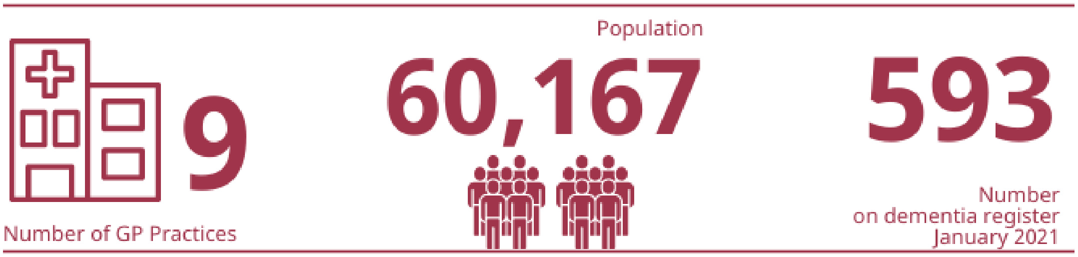
4. Findings: Nithsdale

In this chapter we provide details of the delivery model and impact of the PDS innovation site in Nithsdale.

Context

Nithsdale was one of five localities in Dumfries and Galloway and, with a higher population and expected prevalence of dementia, it was identified as an ideal PDS innovation site. The cluster has nine GP practices with 60,167 patients[11]. In January 2021, there were 593 people on the dementia register.

Figure 4.1 Profile of Nithsdale innovation site.



The next two sections describe the background to activity in Nithsdale and how it was implemented and delivered.

Implementation

Alzheimer Scotland Dementia Link Workers (DLWs) were, and remain, based in the Community Mental Health Team (CMHT). Prior to the project, GPs would refer anyone with a memory concern or cognitive problem to the CMHT for assessment where they would be seen face-to-face by a psychiatrist.

Everyone who received a dementia diagnosis would then be referred to the DLW for PDS based on the Five Pillar model. Elements of support post-diagnosis were also provided by CMHN and HCSW when medication was started, and Home-Based Memory Rehabilitation (HBMR) and other memory strategy work was offered by Occupational Therapy (OT). This model is summarised in the diagram overleaf.

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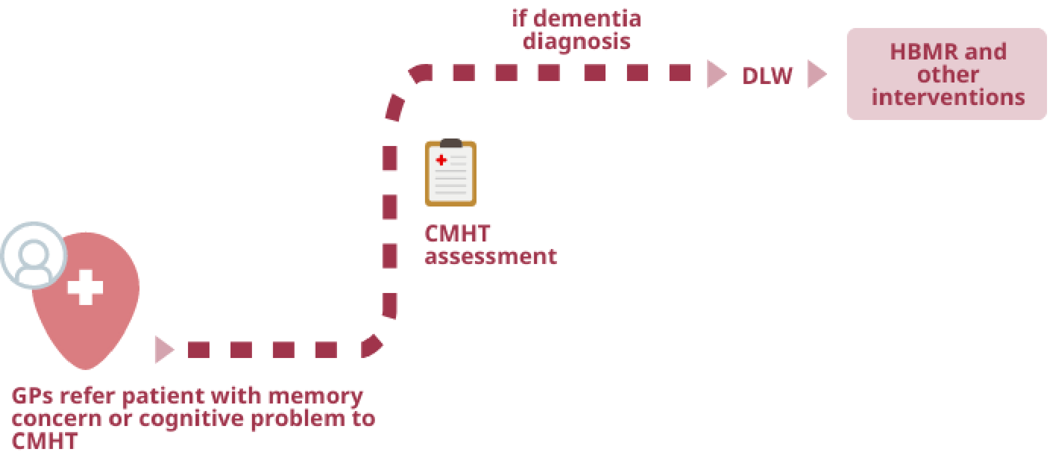
[11] Referred to as the 'Upper Nithsdale and Dumfries' cluster in Public Health Scotland, GP Practice Contact Details and List Sizes, July 2021: https://www.opendata.nhs.scot/dataset/gp-practice-contact-details-and-list-sizes

Figure 4.2 Pre-innovation site model of dementia diagnostic pathway



The initial plan for the innovation site's activity was to increase the flexibility and responsiveness of PDS pathways so that people could access the right support at the right time. The project team sought to develop a

> *"whole system, multi-agency, yet person-centred approach."*

to tackle the increasing waiting times[12] from referral to assessment and PDS. By shifting PDS to primary care, it was expected that provision would become more person-centred and, by helping to remove barriers to diagnosis, diagnosis rates would increase.

The shift of PDS to primary care was to be piloted in the Gillbrae Medical Practice and then rolled out across the Nithsdale cluster. However, the project evolved into a phased approach whereby a new diagnostic pathway was to be developed and tested first and then, in a second phase of activity, changes made to PDS pathways.

The new diagnostic pathway was based on the premise that a specialist Memory Clinic diagnosis may not be necessary for all patients and further informed by the findings from an earlier test of the diagnostic process. In this test, 95 GP referral letters and initial cognitive assessments were randomly selected and assessed by a Consultant Psychiatrist and senior psychologist, and the outcome of the assessment then compared with the diagnosis made in the Memory Clinic[13]. The findings showed that there was agreement in all but seven cases, and four of these had perhaps been more accurately diagnosed by the GP assessment. The test concluded that either route to diagnosis was valid.

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[12] Each CMHT in Dumfries and Galloway had established their own approach to assessment and diagnosis and therefore waiting times varied across the clusters.

[13] Based on information presented by the Consultant Psychiatrist at a British Geriatric Society conference in November 2019.

The implementation of the phased approach was significantly delayed by several factors, most notably by personnel changes and COVID-19. Three different Project Managers have now been in post and, because of these changes, the post was vacant for several months in both 2018 and 2019.

In March 2020, the first national lockdown brought the piloting of the diagnostic pathway to a halt. The pathway was also updated to reflect both the ongoing access restrictions to GP practices and to reflect learning emerging from the pilot. Due to these delays, activity remained focused on the diagnostic pathway throughout the evaluation's lifetime and although changes were made to some elements of the support provided post-diagnosis, the formal PDS pathway (as set out within the Five Pillars Model) was not altered.

Delivery

The project's delivery model evolved over the evaluation period and each iteration of the Nithsdale innovation site model is discussed in turn below.

Model one: Improving PDS and drop-in dementia clinic

In the original model, a new PDS pathway was to be piloted in the Gillbrae Medical Practice and then rolled out across the cluster. It was expected that PDS would be delivered in primary care to 80% of people diagnosed with dementia in the cluster. This delivery model included:

- a new weekly drop-in dementia clinic run by a Band 4 OT Assistant Practitioner[14] in Gillbrae Medical Practice. This was for people with a memory concern or carers in need of PDS or information about dementia more generally
- the opportunity for primary care staff to use the clinic to discuss dementia related issues with the OT
- wider practice-based activities by the OT, including organising information displays and conducting initial cognitive assessments (ACE iii and MoCA), the findings from which were then included in the GP's referral to CMHT
- the Project Manager, who oversaw the new model, supporting primary care staff to reach the appropriate level on the Promoting Excellence Knowledge and Skills Framework.

The Nithsdale workbook shows that 11 patients were seen by the OT in the clinic between January and March 2019.

However, the Project Manager left in May 2018, leading to a pause in these PDS activities and an end to the plans for PDS group work, the creation of a Dementia Friendly GP cluster and the delivery of a DLW developed education programme. Activity subsequently shifted towards the diagnostic process.

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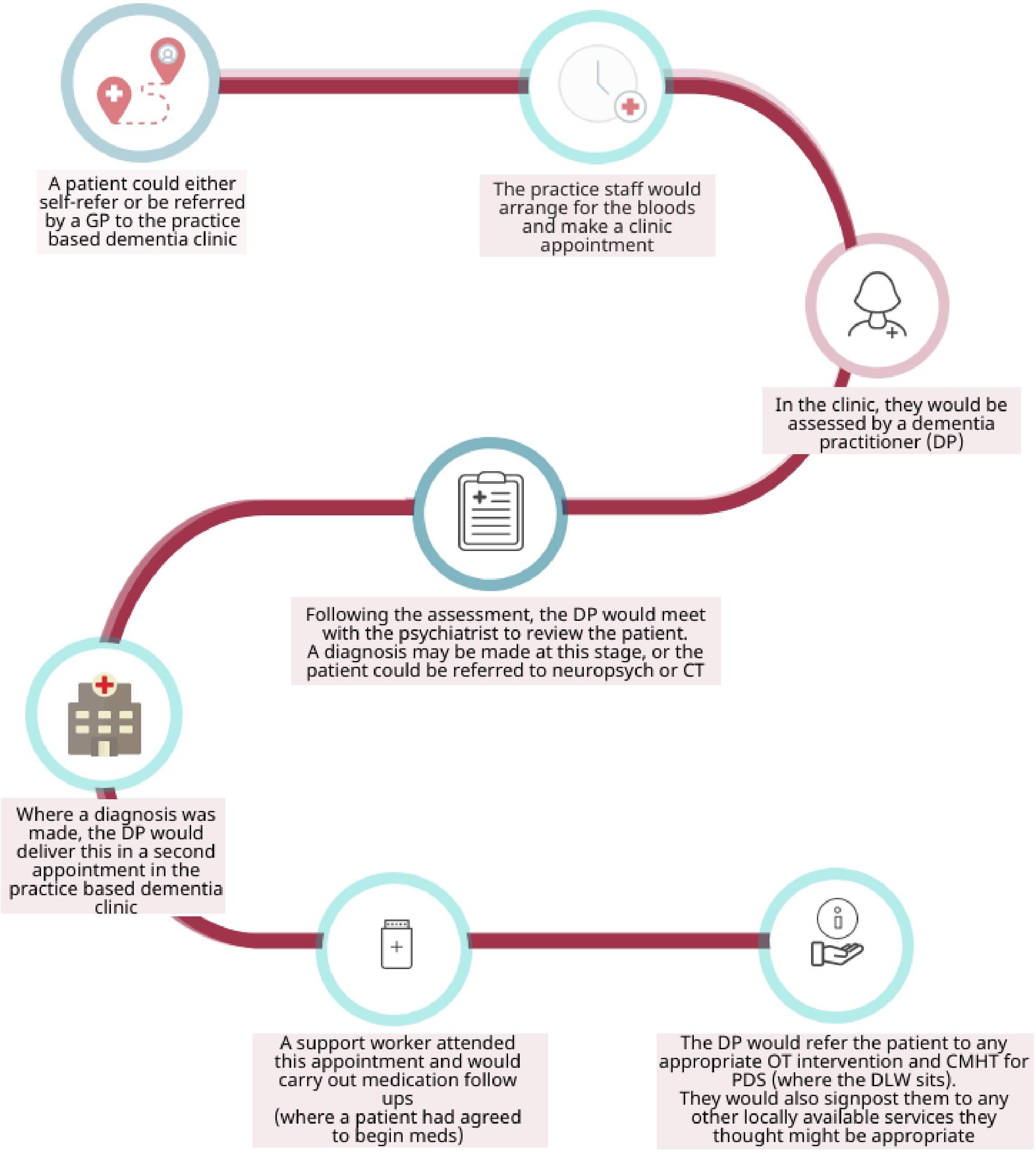
[14] Seconded one day per week

Model two: a new diagnostic pathway

In October 2018, an OT was seconded to work as the new Project Manager and focused on developing a new diagnostic pathway in the months that followed. The new pathway aimed to increase the number of people being diagnosed and reduce waiting times for diagnosis by moving the process from the CMHT into primary care.

Figure 4.3 Model two: A new diagnostic pathway



A patient could either self-refer or be referred by a GP to the practice based dementia clinic

The practice staff would arrange for the bloods and make a clinic appointment

In the clinic, they would be assessed by a dementia practitioner (DP)

Following the assessment, the DP would meet with the psychiatrist to review the patient. A diagnosis may be made at this stage, or the patient could be referred to neuropsych or CT

Where a diagnosis was made, the DP would deliver this in a second appointment in the practice based dementia clinic

A support worker attended this appointment and would carry out medication follow ups (where a patient had agreed to begin meds)

The DP would refer the patient to any appropriate OT intervention and CMHT for PDS (where the DLW sits). They would also signpost them to any other locally available services they thought might be appropriate

Six months later, a band 6 OT was seconded to the role of Dementia Practitioner (DP) one day a week, replacing the band 4 OT Assistant Practitioner who had previously supported the drop-in clinic. The DP was tasked with running a weekly practice-based dementia clinic in Gillbrae Medical Practice. The time in this role was later increased to two days per week so that a fortnightly clinic could be run on a rotational basis in two further cluster practices (Charlotte and Thornhill Medical Practices).

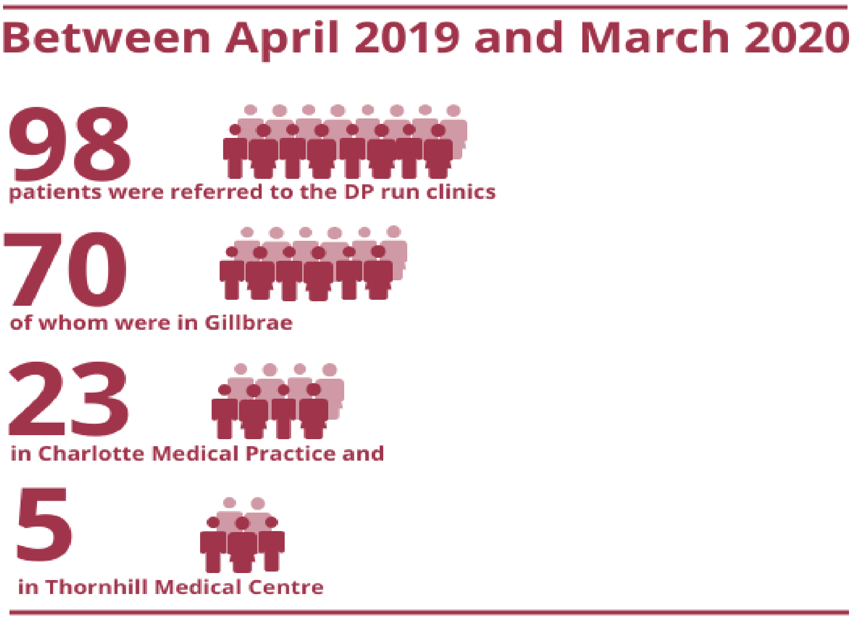
GPs in the participating practices referred patients presenting with a memory concern directly to the DP for assessment and patients could also self-refer with the clinic promoted on TV screens in the pilot surgeries to raise awareness of the service.

Practice staff managed the clinic's diary, booking the appointments and arranging the required blood tests. In the clinic, the DP used a psychiatrist-developed proforma (based on the diagnostic test) to assess each patient. A referral bundle was prepared which consisted of:

- cognitive tests (ACE iii, MoCA)
- bloods
- the proforma
- medical history
- medications
- allergies
- the DP's own notes.

This was reviewed in a meeting between the DP and psychiatrist and when additional information was required, a referral to neuropsychology or CT would be made. Otherwise the diagnosis would be delivered by the DP in the practice-based clinic. Between April 2019 and March 2020, 98 patients were referred to the DP run clinics (70 of whom were in Gillbrae, 23 in Charlotte Medical Practice and 5 in Thornhill Medical Centre).

Figure 4.4: Nithsdale dementia support activity.



Although the Nithsdale innovation site did not directly change the formal PDS pathway, other elements of support were altered. In particular, the DP received support from psychology to manage the emotional impact of delivering a diagnosis and would then, following a discussion with patients, make referrals to sources of support as appropriate. As an OT, the DP would triage people to the OT service at the time of diagnosis, e.g. for home based memory rehabilitation (HBMR) and therefore a separate OT assessement was no longer required.

Other referrals were then made as appropriate to the DLW, Dementia Advisor, CMHT, and Social Work for consideration of care and/or support package, Fire Services for Home Safety Checks, carer support and pharmacy for medication review. Advice could also be sought from the Interventions in Dementia Education Assessment and Support (IDEAS) Team when carer support was required for the management of stress and distressing behaviour. The Nithsdale workbook shows that 56 PDS referrals, where a date of referral was recorded, were made between April 2019 and March 2020.

In June 2019, a Support Worker from the local CMHT started to work alongside the DP, attending follow up appointments after diagnosis and conducting medication reviews in patients' homes.

This pathway continued to operate until early 2020 when the practice-based clinics were brought to a halt by the first national lockdown. All changes made to the pathway, and wider discussion around formal PDS beyond March 2020 are summarised in the model three section later on in this chapter.

Economic analysis

The move to diagnosis of dementia in Nithsdale being led by the Dementia Practitioner rather than through a Consultant Psychiatrist supported by a Community Mental Health Nurse (CMHN) has allowed for a more efficient use of NHS resources in the diagnosis of dementia.

The Consultant Psychiatrist interviewed as part of the evaluation suggested that the model could reduce the time from referral to diagnosis. This would have a clear patient benefit, reducing uncertainty and any associated concerns. Speedier diagnosis should be seen as a patient benefit but one that cannot be readily quantified from an economic perspective. The economic analysis therefore focuses on the time spent by clinicians on diagnosis.

Nithsdale were able to provide detailed data on the staff involved with assessment and diagnosis and the time spent at each stage with the Dementia Practitioner led model as opposed to the Consultant Psychiatrist approach used previously. Costs of each professional were taken from published sources[15] and applied to the time taken to perform activities to estimate the difference in costs to the NHS for each model. This is summarised overleaf.

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[15] Personal Social Services Research Unit (PSSRU): Unit Costs of Health and Social Care 2020

Table 4.1: Costs of diagnosis pathways

Model	Activity	Professional (and band if relevant)	Time on activity (mins)	Cost per hour	Cost per activity
Dementia Practitioner led (new model – pre COVID)	Assessment	Dementia Practitioner (Band 6)	60	£89	£89
	Review of assessment and diagnosis deliver	Dementia Practitioner (Band 6)	70-80	£89	£104-£119
		Consultant Psychiatrist	10	£120	£20
	Medication review	CMHT support worker (Band 3[16])	60	£31	£31
	Total cost				**£244-£259**
Consultant Psychiatrist led (old model)	Pre-memory clinic assessment	CMHN (Band 5 or 6)	90	£63-£89	£95-£134
	Review of assessment and diagnosis deliver	Consultant Psychiatrist	120	£120	£240
	Total cost				**£335-£374**

GP referrals were required for both models so GP time was excluded from the analysis. It was assumed any diagnostic blood tests, scans or GP administration would also be the same between models.

On the assumption that the quality of diagnosis was the same (no evidence was found that the quality of diagnosis had deteriorated using the new pathway), and depending on the actual time taken for specific activities and band of staff performing the activity, the saving to the NHS with the Dementia Practitioner led model for diagnosis in Nithsdale was between £56 and £134 per diagnosis.

There were 82 diagnoses of dementia made between 2019 and 2020 in Nithsdale via the new pathway. The potential total savings with the new pathway for a diagnosis were likely to be no lower than £4,592 and could be as high as £10,988.

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[16] Costs of Band 3 unavailable in PSSRU so used the cost of a Band 4 professional staff resulting in a slight overestimate of cost of Dementia Practitioner model

Figure 4.5: Comparative cost per diagnosis and estimated savings

£56 - £134

per diagnosis

Estimated potential total cost savings

£4,592 - £10,988

(based on 82 diagnoses in 2019 - 20)

Evaluating the Nithsdale innovation site

As described in chapter 2, visits to Nithsdale and review of documentation (like the driver diagrams and project outcomes) informed the evaluation plan for the project. The evaluation plan was based on model 2, the pathway being piloted at that time, and a series of outcomes were identified that reflected current activity. In the final version of the plan the key outcomes were to:

- increase the number of people being diagnosed with dementia
- improve the confidence of primary care staff in supporting people with dementia
- create closer links between primary care and specialist mental health services to ensure timely and accurate diagnosis as a result of the innovation site
- ensure innovation site work results in a sustainable and transferable framework for PDS in Dumfries and Galloway.

Table 4.2 summarises the breakdown of the contributors and table 4.3 provides the details of the local staff and stakeholders.

Table 4.2: Evaluation participants in Nithsdale

Project managers/PDS staff	Local partners/collaborators	People with dementia	GP survey responses
2	7	1	3

Table 4.3: Local staff and stakeholders

Project managers/PDS staff	Local partners/collaborators
Post Diagnostic Support Lead, NHS Dumfries and Galloway Dementia Practitioner, NHS Dumfries & Galloway	Consultant Old Age Psychiatrist, x2, NHS Dumfries & Galloway Dementia Link Worker, Alzheimer Scotland Occupational Therapy Service Manager, Dumfries & Galloway Council IDEAS Team Lead, NHS Dumfries & Galloway

Project managers/PDS staff	Local partners/collaborators
	Lead Nurse CMHN, NHS Dumfries & Galloway Sustainability and Modernisation (SAM) Board Representative, Dumfries & Galloway Health & Social Care Partnership Improvement Advisor – HIS[17]

The interviews with staff, local stakeholders, service users, and the GP survey responses inform the next section which describes the impact of the pilot project.

Impact of the pilot project

Although the new diagnostic pathway was rolled out to two further practices, it was only in place between October 2019 and February 2020 before the COVID-19 pandemic. Therefore, much of the information from the discussions with key staff and from the GP survey reflects the focused activity in one pilot practice and, as the development of both the diagnostic and new PDS pathways continues, additional impacts can be expected to emerge beyond the lifetime of the evaluation. Nevertheless, the available evidence suggests the diagnostic pathway pilot in Gillbrae Medical Practice has brought about change. These changes, and expected future impacts, can be grouped into three broad categories:

- diagnosis
- patient experience
- communication between primary and secondary care staff.

A new diagnostic pathway

Number of diagnoses and time to diagnosis

The project team chose to focus on diagnosis in the first phase of activity because the diagnosis rate was observed to fall below the expected prevalence rate. Analysis of the workbook shows that 82 people were diagnosed with dementia via the new pathway in three practices within the Dumfries and Upper Nithsdale GP cluster.

The interviewees described how the new pathway had reduced waiting times and the workbook data suggests that despite fluctuations arising from factors such as staff absence, the average time from referral to diagnosis was reduced from nine months (reported by the project) to 53 days (based on evidence from the workbook) in the test sites.

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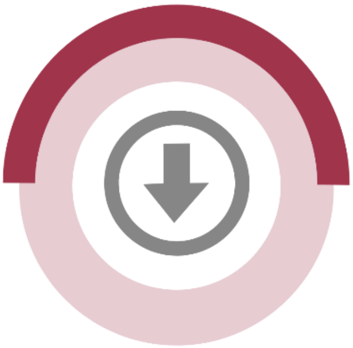
[17] This interviewee was not included in the numbers in Table 4.2 because she was interviewed twice as the Improvement Advisor and as a national stakeholder.

Time from referral to diagnosis:



252 days → 53 days

Furthermore, as the new pathway removed the need for a face-to-face psychiatrist appointment for non-complex cases, waiting times in non-test sites were also reported to have decreased:

"The other thing that we noticed was this, because it relieved a lot of the strain within our team, the team members were free to look at other cases as well. So actually, it released time and the whole of our service found that the waiting time had reduced."

In considering how the rollout of the new pathway may create similar impacts elsewhere within Dumfries and Galloway, it was important to acknowledge that as each CMHT had established its own assessment and diagnosis procedures similar reductions may not be experienced elsewhere. However, the roll out will remove variation and ensure a standardised approach.

Removing barriers to diagnosis

In addition to reducing the time from referral to diagnosis, some interviewees suggested that by enabling GPs to refer directly to a practice-based clinic, some of the barriers to diagnosis were removed and patients were referred earlier. These interviewees described how a memory concern was often raised at the end of a GP appointment, or a memory issue was identified during an appointment, leaving GPs with little time to explore the issue:

> *"So they found it really useful to have that service support there so they knew that they could then book them into that slot."*

Instead of a follow up appointment, the GP would mention the clinic to patients and then refer directly to the clinic where appropriate. The responses from primary care staff completing the survey support this perception; for example, one stated that a patient:

> *"Could be referred to someone who had more time to gather the required information"* and another that it *"encouraged them to refer more"* and that the systems had been *"made easier."*

Although GPs may have referred patients for an assessment sooner than they would have without the practice-based clinic, there was mixed evidence on whether patients with a memory concern were coming forward any earlier. Patients could self-refer to the clinic and this service was advertised on TV screens within the waiting area. However, the workbook data indicates that only one self-referral was made and three referrals made by a family member. While two of the primary care staff completing the survey felt that an increased number of patients came forward for an assessment, and all three interviewed perceived awareness of the benefits of an early diagnosis to have increased to either a small or large extent amongst patients, an interviewee recognised that more work was needed:

> *"I still think there's a lot of work to be done with people about what's stopping people going early, because often a lot of the cases that were coming through were still pretty [late], it was family that was raising concerns. They were picking up people who were really quite late on in their journey."*

The patient interviewee described how they did not come forward for assessment, but rather presented with a memory issue whilst attending the practice for an unrelated appointment. A discussion with a nurse then led to a referral to the practice-based clinic. The patient felt that they might have come forward at some point, but they were unlikely to have done so at that time because:

> *"I probably didn't want to know."*

Increased confidence and knowledge about supporting people with dementia

One of the project's earlier change ideas had been that GPs, with the support of psychiatrists, would diagnose non-complex patients:

> *"A fringe objective was to move towards GPs diagnosing, but we haven't really done much of that. It's about the process of change and this would be the first step in the road to that, but it's a long game. The benefits we're seeing are in the wait times and reducing consultant time."*

Although GPs diagnosing has not happened, practice staff completing the survey indicated that their understanding of dementia assessment and diagnosis had increased by either a small or large extent. Furthermore, an increase in their confidence in referring and caring for patients with a memory concern and dementia was also reported in the survey. More broadly, two out of the three primary care staff felt that their practice was now more dementia friendly.

Patient experience

There were several examples of the impact of the new pathway on the patient experience.

Delayed PDS

The available data identified several mechanisms through which the new diagnostic pathway may have affected patient experiences of their support. Firstly, interviewees acknowledged that the new pathway resulted in an increased number of people being diagnosed and this meant that the DLW's waiting times increased. Despite this, the pathway for formal PDS remained the same and referrals to the DLW continued to be made to CMHT at the time of diagnosis. Their increased caseload meant a longer waiting time for PDS. Between July 2019 and January 2021, the caseload ranged from 91 to 115 and therefore the ability to provide quality PDS was questioned:

> "*It's nice in a sense to have a formal diagnosis, then people know what's wrong and gives them access to support. But unless there's enough support, what's the point*?"

Other elements of support post-diagnosis

More positively, a seconded OT carried out the DP role within model two which meant that they were able to refer patients for home based memory rehabilitation (where it was appropriate) or other interventions directly without the need for an additional assessment by the OT service. Therefore, inappropriate referrals and waiting times were reduced for this aspect of support post-diagnosis. In addition, the local knowledge held by the DP meant that they were also able to refer to other sources of support within the community (e.g. local groups such as Food Train, Befriends). One interviewee felt that this had led to a shift in the perception of the nature of PDS:

> *"Whereas before PDS was seen as falling to the DLW, I suppose there's more of a recognition now that the PDS starts far sooner. And now that it's a clinician who's feeding back that diagnosis, it probably starts from that first appointment so you're likely to get far more questions and I suppose the home based memory rehab is classed as PDS now as well, whereas maybe it was seen as a separate entity before."*

Within the current model (model three), efforts are being made to preserve the benefits arising from OT input at the time of diagnosis and wherever possible, an OT will attend the review meeting between the CPN and psychiatrist. Furthermore, all three primary care staff completing the survey felt that their awareness of PDS had increased, which may lead to continued benefits beyond the lifetime of the project.

Greater continuity of care

Wider benefits arising from the changes made to diagnosis were also reported: shifting the delivery of diagnosis from the psychiatrist to either a DP (model two) or CMHN (model three) was reported to improve the continuity of care. In the clinic run in Gillbrae Medical Practice, a Health Care Support Worker would attend the appointment in which the diagnosis was delivered (alongside the DP) and then conduct the follow up medication review.

> *"The thing that I like about the fact that it's the clinician whose completed the assessment who then also feeds back the diagnosis, is you've got that continuity for the patient, you've already started to build rapport with them and they know you."*

In addition to providing patients with a "*face to recognise*", interviewees suggested that both the DP and CPN are better positioned to answer patient questions at the time of diagnosis because of either their ability to spend more time with them, or patients' perceptions that they can be more readily questioned than a consultant.

More broadly, the move from the traditional CMHT memory clinic pathway to primary care was brought about in recognition that not everyone required specialised CMHT input. The new pathway aimed to move away from this '*one size fits all*' approach that felt "*very unwieldy and not necessarily the correct thing for all people"* towards a more person-centred approach. For one interviewee, who emphasised that dementia was both a social and medical condition, it was felt that the shift could lead to more discussion on what a diagnosis might mean and whether it was the right step for each individual. In doing so, they perceived it as enabling people to *"get ahead of the pathway"* and establish shared decision making from the outset:

> *"Diagnosing people as early as we can gives them their best chance of living well for longer, more independently for longer, so they get a better outcome. There's equality issues in, if people are diagnosed early and they've got the information that they need, they're less likely to face inequities in how they're treated accessing any service because they so happen to have dementia, that secondary care specialist services isn't the right place for people, they were limited in what we could offer."*

However, interviewees did acknowledge that there was some initial concern as to how patients would respond to a remote diagnosis:

> *"We thought that the patients and families might feel that they're being neglected by not having a doctor to do face-to-face contact, but it seemed to be ok, the fact that they had a fairly senior nurse involved in the discussion and that the nurse was in contact with a doctor and the diagnosis was still coming through the doctor, that seemed to be satisfactory."*

Although several interviewees emphasised that patients could still see the consultant if they would like to, the one patient interviewed described how it "*felt that there was a wee bit missing somewhere as regards seeing someone like the psychiatrist or even to say, 'this is the diagnosis.'"* Although interviewees commonly expressed confidence in the quality of the diagnosis delivered through the new pathway, the lack of face-to-face contact with the Consultant Psychiatrist meant that they could not independently assess a person's ability to continue driving. As a result the OT Service Manager reported an increase in referrals for a Rookwood Driving Assessment to support this decision.

Improved relationships between primary and secondary care

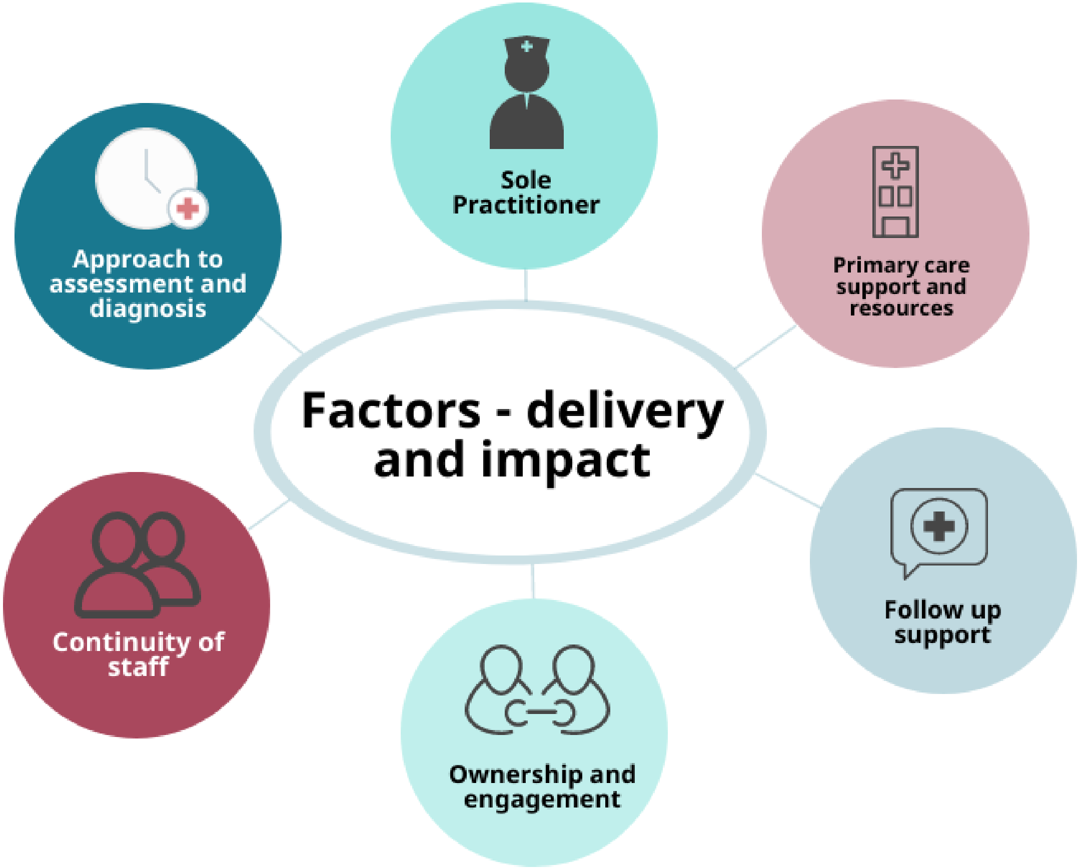
The shift in the diagnostic pathway created new opportunities for primary and secondary care staff to interact. Overall, the presence of a clinic within a GP practice was perceived positively amongst interviewees and both survey respondents who noted a change stated that communication between the practice and community mental health services had increased to a large extent.

The available survey and interview data suggests that the presence of the DP in the practice created opportunities "*to shuffle down the corridor and talk"* and therefore increase informal dialogue and information sharing. The DP was able to suggest possible actions to the GP and similarly, the GP could advise the DP on any issues relevant to those attending the clinic.

Learning, enablers, and barriers

The general consensus from those involved in the piloting of the new diagnostic pathway in Gillbrae Medical Practice (model two) was that when the pathway worked, it worked well. However, it was widely recognised that the model was dependent on a single practitioner and did not function during their absence. Removing this dependency has been instrumental in guiding the pathways redesign and this factor and other barriers and enablers are summarised in the diagram below and discussed in more detail.

Figure 4.6: Nithsdale – factors affecting delivery and impact



Sole practitioner

The new diagnostic pathway piloted in model two was dependent on the availability of two practitioners, the DP and Consultant Psychiatrist. In the absence of the DP, clinic appointments would be cancelled and the psychiatrist's absence would lead to a delay in a diagnosis being made. The lack of resilience within the pathway was acknowledged by interviewees and most described how it "*fell apart*" during longer periods of absence. Therefore, the "*reputational, clinical and financial*" risks were recognised and a wider team approach identified as a means of mitigation. In the updated pathway (model three), the assessment process has returned to CPNs and cover for the psychiatrists agreed to ensure that the pathway can continue during any absences.

Primary care support and resources

Several resources within the GP practices hosting the clinic within model two were also identified as enablers. Firstly, administrative support from practice staff was widely perceived as being instrumental to the effectiveness of the pathway. One member of the pilot practice team in particular was identified by several interviewees as a "*lynch pin*" in facilitating the shift from secondary to primary care:

> *"They were almost like an interface between us who were based in secondary care and the GPs who were based in primary care."*

Their role included arranging for bloods to be taken before the clinic appointment, scanning notes and making SCI gateway referrals. Practice staff would also manage the diary for the clinic which enabled appointments to be made easily and quickly. However, the downside for the DP and wider OT service was they could only access the system at the practice, so if they were out and needed to cancel an appointment were unable to access to.

Other practice factors identified as important enablers included:

- an on-site pharmacy – after a diagnosis had been made, the practice team were able to liaise with the pharmacy so that a prescription was prepared in advance of an appointment. This meant that when a patient chose to begin medication at the time of diagnosis, they could leave the practice with their prescription
- the availability of a room – in many practices space was at a premium and when there was a dedicated room that could be used it made the practicalities of delivering the clinic much easier.

Follow up support

Seconding an OT and Health Care Support Worker to work in the new diagnostic pathway one or two days a week meant that there was no central contact point for follow up queries from patients and carers However, follow up medication reviews were conducted by the Health Care Support Worker and after a discussion on the most appropriate route for more complex issues, it was agreed they would be relayed to the psychiatrist. In the latest version of the pathway (model three), patients are now able to contact their local CMHT with any queries, removing dependency on the availability of a single practitioner.

Ownership and engagement

As with any test of change, securing the buy-in of different services was essential to its implementation and allowing time for new processes to embed was important. A small number of interviewees questioned how different services had been engaged within the project's activity. There was a feeling amongst those who had not been involved in the development of the diagnostic pathway in model two that they had been excluded from discussions:

> *"I think open communication would be a huge help, I don't know that there's been a huge amount of that over the past few years. I don't think there's*

> *been a lot of listening to very, very experienced clinicians, and I'm not just talking about myself I'm talking about all disciplines who expressed concerns, that's been a huge barrier."*

Most recently, under the new model, a Steering Group has been formed and the Project Manager – a registered CMHN – has sought to engage with all key stakeholders including CMHNs, GPs, OTs, DLWs, Psychiatry, Psychology, Alzheimer Scotland and Commissioning. As part of this engagement, the Project Manager has emphasised the value of the CMHT's CMHN input.

Psychiatry – as the original architect of the new pathway via their test of change – were on board from the outset and the project team met with cluster leads and practice staff in the early stages of the project creating what was described by one interviewee as a "*fantastic*" relationship. Latterly, the strain on primary care throughout COVID-19, and particularly during the vaccine rollout, created engagement challenges in developing of the most recent pathway. There was a perception amongst interviewees that GPs liked the presence of a practice-based clinic and the time savings this brought.

Continuity of staff

Throughout the lifetime of the Nithsdale innovation site activity, three different project managers have been in post and each personnel change has brought about a delay. However, a small number of personnel have been involved from the outset and this continuity has created opportunities to sustain the pathway. For those who have been involved throughout the pilot in one form or another, and therefore aware of the early impacts emerging from the piloting of the pathway, there was a recognition that it could be rolled out beyond Nithsdale. The sustainability and spread of the activity is discussed later in this chapter.

Approach to assessment and diagnosis

To ensure that the assessment was completed in the same way, regardless of who the assessing practitioner was, and that the information collated during assessment was available to the wider team, a template has been updated for use in the diagnostic pathway in model three. This will create a more sustainable and safe approach. The appointment time has also been increased from 60 to 90 minutes to ensure sufficient time to complete the assessment and associated paperwork (during model two, this had to be completed during breaks and after hours).

Differences in how best to capture the views of family and carers were also reported in the interviews. Within the practice-based clinic, the patient would attend a one hour appointment with a family member or friend. One interviewee felt that this was beneficial, particularly amongst patients with a later stage of dementia. However another felt that it could potentially create barriers to full disclosure by either the patient or accompanying person (who may have been reluctant to fully express their concerns in front of each other). In response to this, the updated pathway (model three) provides a family member or carer with a separate proforma in which they can submit their perceptions and experiences while the patient completes the assessments.

The relative merits of a CMHN versus OT led assessment were also discussed in the interviews. An OT was seconded for both pragmatic and good practice reasons; capacity within the OT service was identified at the time the pathway was being designed and those leading the work had the authority to draw upon it. The potential benefits of an OT's dual mental and physical health training to the role were also highlighted and one interviewee perceived this as being particularly well suited to a condition that was both medical and social. However, a small number of interviewees questioned why what had traditionally been a CMHN role had been assigned to an OT. Within the updated pathway (model three) assessments have been returned to the CMHNs and, in a new role, they will now also deliver the diagnosis. This has been introduced following more far reaching changes to the way in which CMHNs work during COVID-19 (for example shift patterns have been changed and the crisis and community teams amalgamated). The project team have focused on building relationships with the CMHNs to overcome negative perceptions of the project and remove any concerns that may surround further change.

Lessons learned: Developing model three

The approach taken in Nithsdale always aimed to achieve whole system change but its focus shifted throughout the project. Many lessons have been learned from the delivery of the first two models and the project team are working to harness these in the updated version of the pathway now being implemented.

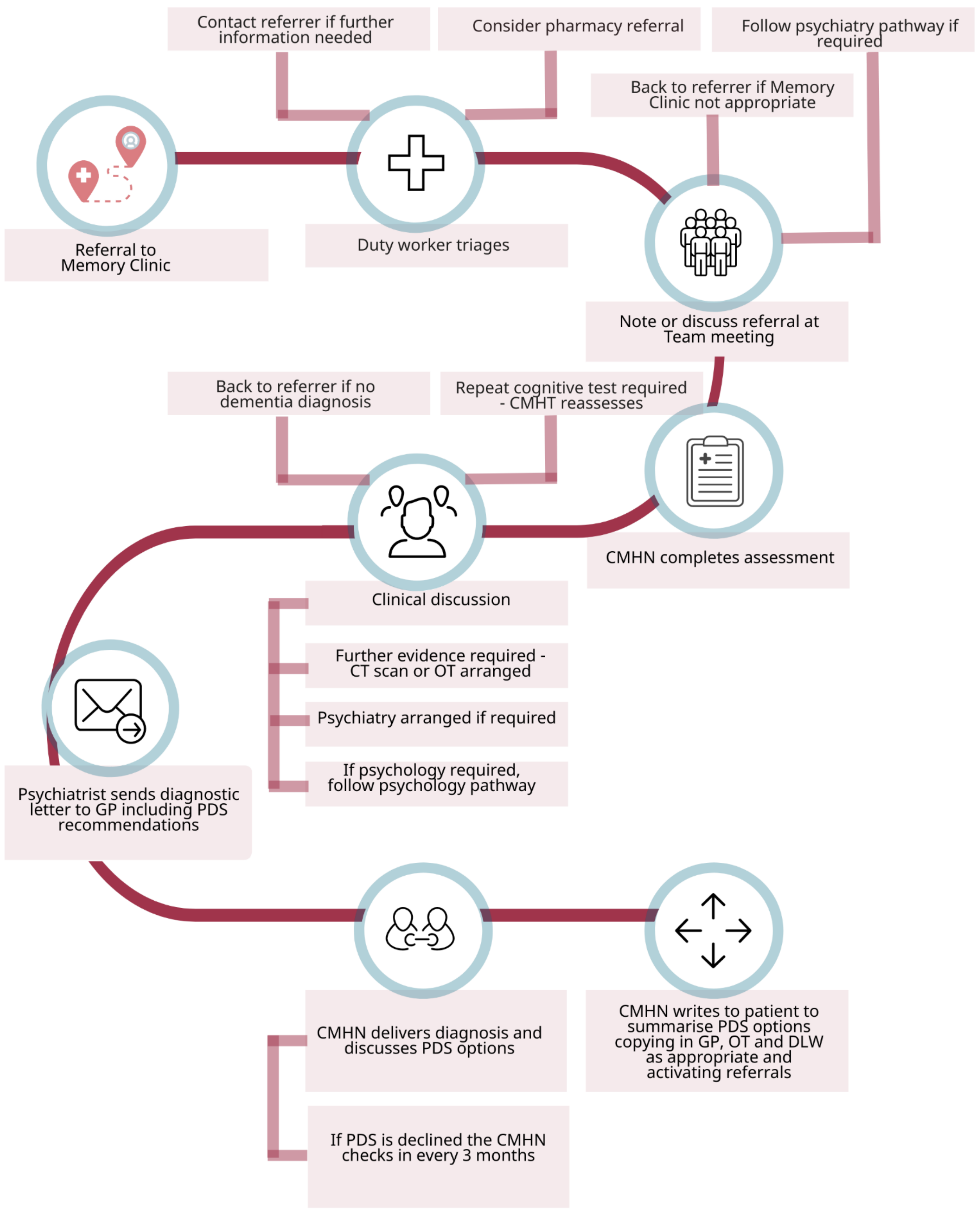
A key focus has been to build additional resilience by removing the dependency on a single practitioner. This, alongside COVID-19 restrictions, brought an end to the practice-based clinic and the remote diagnosis pathway shifted to CMHNs within CMHTs. The CMHNs will now deliver the diagnosis following a case review with the Consultant Psychiatrist. By enabling the CMHNs to assess and then deliver a diagnosis, continuity in care could potentially be increased. The involvement of the CMHTs was also expected to remove earlier difficulties in establishing a point of contact for patient queries when the DP was not in the clinic. Further benefits of the second model might be retained should OT participate in the case review and therefore remove the need for a separate assessment by the service.

However, not all of the positively perceived elements of the first two models have been retained; the practice-based clinic was widely welcomed by interviewees but an opportunity to maintain this while operating at scale continues to present challenges. At the time of data collection, the project team were exploring opportunities to reintroduce a practitioner into GP practices. The need for changes to PDS has also been recognised; if the number of diagnoses increased and the time from referral to diagnosis reduced, change would be needed to ensure patients do not face a longer wait for formal PDS. Alongside the implementation of model three, the project team were planning to make improvements to PDS to ensure access to patient centred support when it was needed.

Model three: Developing the pathway post-COVID

Work since March 2020 has focused on updating the pathway and its associated processes.

Figure 4.7: Current Memory Clinic diagnostic pathway



The changes made include the introduction of a new patient leaflet designed with the support of the IDEAS team. These are now given at each appointment so that patients' have a record of who they have seen, what has happened and who to contact. In addition, those people who had already been referred for assessment, or were awaiting the results of an assessment, were triaged and contacted to identify where intervention was needed. The assessment proforma has also been adapted and made more robust to mirror the generic mental health assessment which incorporates mood and anxiety and enables carers' views to be captured separately.

More fundamentally, the pathway itself has been redesigned to remove its single practitioner dependency and enable it to be scaled up and sustained. In the updated pathway, a remote psychiatrist diagnosis remains but the assessment would now be carried out by CMHNs in the CMHTs.

Following the assessment, the CMHNs meet the psychiatrist via Microsoft Teams or face-to-face to review each case and then deliver the diagnosis. Wherever possible, OTs attend the review meeting to assess the appropriateness of referrals to either HBMR or other interventions, and in doing so, maintain the fast track access to OT established in the previous version of the pathway. A Health Care Support Worker continues to conduct the follow up medication review as in model two. To support these new elements of the CMHNs role, Psychiatry and Clinical Psychology provided training to the CMHNs in the relevant clusters and this will extend to other areas as the new model rolls out.

In May 2021, patients began accessing the new diagnostic pathway in these areas.

Sustainability and spread

Dumfries and Galloway's Health and Social Care partnership are leading a region wide Sustainability and Modernisation (SAM) programme. The programme has three workstreams: planned care; urgent and unscheduled care; and community health and social care. At the time of the evaluation's fieldwork, the project team were preparing to submit a SAM Mandate as part of the planned care workstream. The testing and subsequent roll out of the new pathway will be expected to take place under the umbrella of the SAM programme and ensure that improving dementia diagnosis remains a priority within the region.

Also as part of the SAM programme, new multi-disciplinary Home Teams have been introduced to provide person-centred care in communities. The new teams will link with practices to help manage those with the most complex needs at home. Their introduction provides opportunities to build relationships with the health and social care partnership.

At the time of the fieldwork, the project team had began reviewing formal PDS provision and opportunities for change alongside their work to improve the diagnostic pathway. In the absence of an extension to the innovation site activity, it was intended that there would be small tests of change focused on how PDS was recorded so that it could be defined more broadly than DLW support.

However, as part of the SAM programme, the project team are now aiming to bring about whole system change. Following a recent scoping exercise of patients' journeys through PDS, where one person was identified as receiving eight visits from four professionals, planned activity will focus on developing a more multi-disciplinary and co-ordinated approach. In doing so, it was expected that duplication will be reduced and earlier access to support facilitated, which in turn should lead to a more person-centred approach.

Although work at the time of the evaluation had focused on a small number of test sites, it was expected that the SAM Mandate will provide a pathway with increased resilience and improved sustainability. More broadly, the mandate was expected to provide a platform for wider discussions with local stakeholders:

> *"I think having the rigor of the SAM Mandate wrapped around this work will help us to negotiate with the boards and the directorate that this is a priority."*

Summary

As innovation site activity in Nithsdale continued, it was expected that further change and impact will emerge beyond the lifetime of the evaluation. However, progress against the target outcomes at this point can be summarised as:

- **Increase in number of people being diagnosed with dementia:**
  Although more people were diagnosed in 2019 than in 2018 in the areas where the test practices were located, only three out of the nine cluster practices participated in innovation site activity. With the limited available evidence, no robust conclusions can be drawn.
- **Primary care staff have improved confidence in supporting people with dementia:**
  Limited evidence available from the survey of practice staff indicates that both understanding of dementia diagnosis and confidence in referring and caring for people with dementia increased. However, the updated diagnostic pathway takes place outwith primary care and its implementation began outside of the data collection period. It was therefore not known if further benefits beyond the initial test sites can be achieved.
- **There are closer links between primary care and specialist mental health services to ensure timely and accurate diagnosis because of the innovation site:**
  A practice-based clinic was perceived to have enabled increased communication between these services. But again, because of the absence of a presence in primary care in the current version of the pathway, it was unknown if and how these benefits will be maintained.
- **The innovation site results in a sustainable and transferable framework for PDS in Dumfries and Galloway:**
  If the new diagnostic pathway and work to improve PDS continues as part of the wider SAM programme, then wider and sustained change could be achieved.

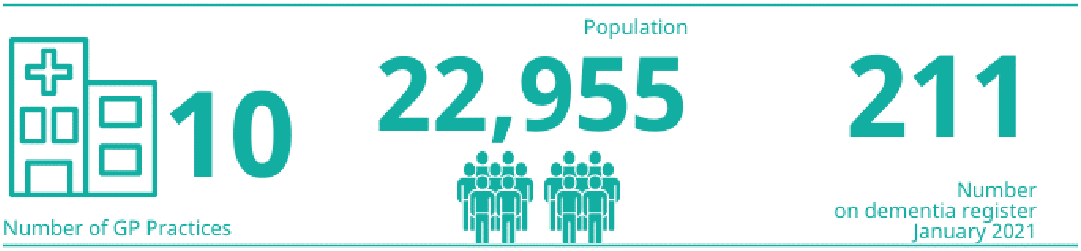
5. Findings: Delivery and Impact – Shetland

In this chapter we provide details of the delivery model and impact of the PDS innovation site in Shetland.

Context

The Shetland cluster covers 16 inhabited islands and was co-terminous with Shetland Health and Social Care Partnership. It has ten GP practices with 22,955 patients[18] and, in January 2021, there were 211 patients on the dementia register.

Figure 5.1: Profile of Shetland innovation site.



This section describes the background to the innovation site work in Shetland and how it was delivered.

Implementation

Dementia diagnosis pathway in Shetland

The Dementia Assessment Service (DAS) was established in Shetland in 2010. This was a nurse-led model, where, following referrals from GPs, nurse practitioners assess patients for dementia, make diagnoses and formulate treatment plans. This process involves a 90 minute assessment with a 60 minute follow up appointment to discuss diagnosis, along with regular reviews if the patient was on medication. The time from referral to diagnosis was generally around two to four weeks.

The DAS was supported by weekly video conferences with a consultant Old Age Psychiatrist based in Aberdeen to discuss referrals, diagnoses and treatment plans.

This replaced the old model, where the diagnosis pathway was more variable. Most diagnoses were made by local consultant physicians or GPs and most were diagnosed as unspecified dementia rather than the a more specific type of dementia. People were then less likely to receive cognitive enhancng medication when given an unspecified diagnosis. Diagnoses were sometimes made by specialist consultant psychiatrists and more complex cases were referred for

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[18] Public Health Scotland, GP Practice Contact Details and List Sizes, July 2021: https://www.opendata.nhs.scot/dataset/gp-practice-contact-details-and-list-sizes

outpatient or inpatient assessment in Aberdeen. In these cases, diagnoses could take several months to be confirmed.

Delivery

Post-diagnostic dementia support in Shetland

In 2013, when the HEAT target related to the delivery of a year's worth of PDS was introduced, responsibility for delivering this was delegated to Shetland Islands Council’s Adult Social Care department. This was a team of 21 people working with vulnerable adults. Supporting people with dementia was only part of their role, and they were expected to take on this responsibility on top of their existing caseload.

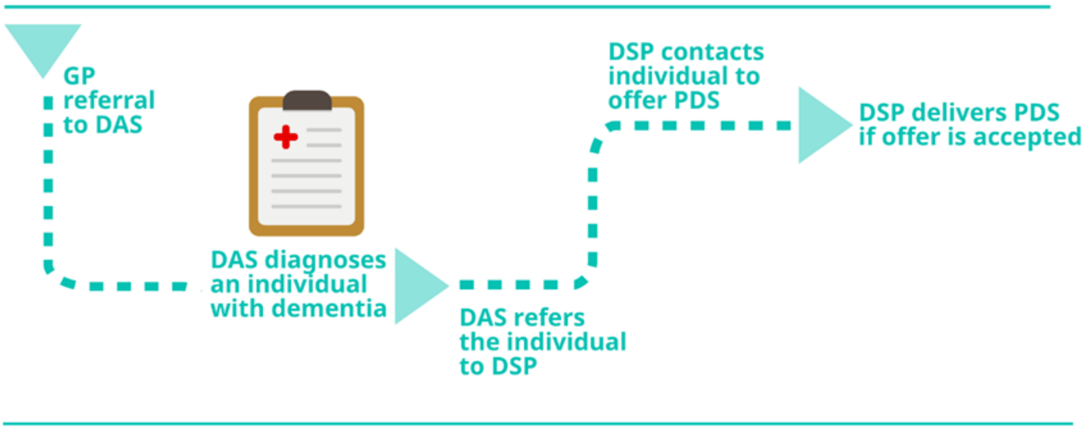
An internal audit of PDS in Shetland was undertaken in 2018. This found issues with the way in which PDS was being delivered. As it was an add-on to the team members’ roles it restricted the extent of support that the team was able to offer. Stakeholders felt there was *“no real structure to it”*, with a lack of consistency in the support delivered across the team, and there was low uptake of PDS among people with dementia.

When the Scottish Government and HIS advertised for areas to appply for funding to take forward innovative approaches to delivering PDS in primary care settings, Shetland HSCP took the opportunity to try a different approach. After a successful application, DAS and Shetland Islands Council’s Occupational Therapy team worked closely together to develop a job specification for a new role, the Dementia Support Practitioner (DSP) dedicated to leading the delivery of PDS in Shetland. An individual who had been working as part of the social care team and who had previously worked as a Community Mental Health Nurse, and who had been identified as delivering good quality PDS, was seconded to the role in Autumn 2017.

The DSP’s role was to deliver PDS, under Alzheimer Scotland’s 5 Pillars Model, including emotional and practical support and advice to help people with dementia and their carers.The DSP provided referrals to and information about other public and third sector agencies that could provide support.

The DSP worked closely with the DAS to provide a seamless link from diagnosis to PDS. When an individual was diagnosed with dementia, he or she was automatically referred to the DSP, who contacted the individual to offer PDS. This pathway is illustrated below.

Figure 5.2: Dementia support pathway in Shetland.

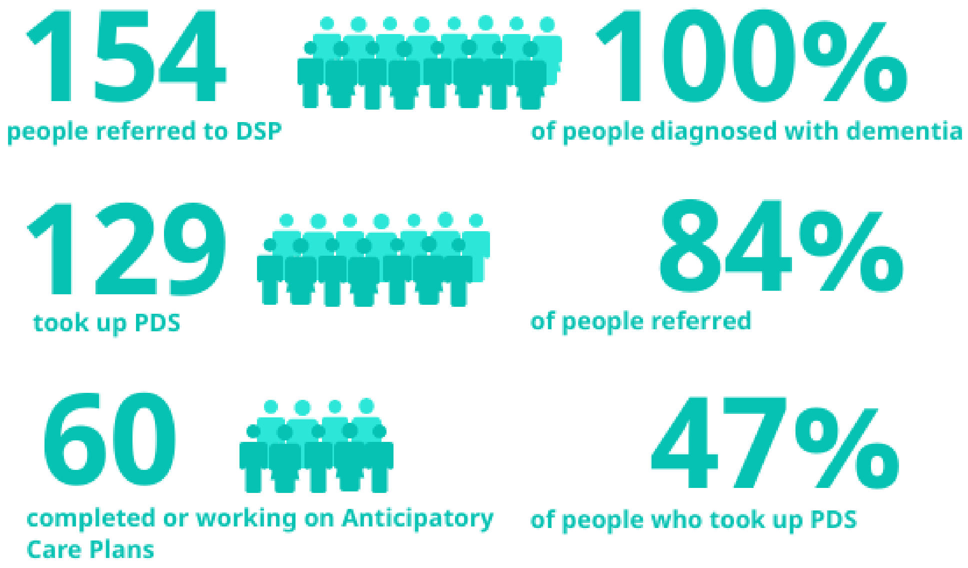


Initially, the DSP was based in the Occupational Therapy department, but relocated to the DAS office in order to enhance collaborative working with the DAS team. The role remained line managed by Occupational Therapy, however, and retained close links with that service.

The DSP worked closely with other services too. There was close joint working with DAS, and the DSP attends locality meetings to engage with other health and social care professionals. There was also a meeting between DAS, the DSP and Alzheimer Scotland every fortnight to help co-ordinate the support delivered to people living with dementia.

The diagrams below illustrate some of the key statistics about the support delivered by the DSP since she was appointed.

Figure 5.3: Shetland dementia support activity (please note the 100% refers to people known to have a new diagnosis of dementia in Shetland)



Economic analysis of cost of nurse-led assessment and diagnosis model

The DSP's role was part of the DAS team, which was established in 2010 and represented a major change in the dementia assessment and diagnostic pathway in Shetland. In this section, we provide an economic analysis of the cost of the current nurse-led pathway compared with the old one.

As described earlier in this chapter, the nurse-led dementia diagnostic pathway in Shetland replaced a previous approach to dementia diagnosis that was disjointed and variable. Table 5.1 summarises the costs of diagnoses under the nurse-led pathway compared with the previous process, based on information about the time taken to make diagnoses provided by the DAS team.

Table 5.1: Costs of diagnoses

Model	**Activity**	**Professional (and band if relevant)**	**Time on activity (mins)**	**Cost per hour**	**Cost per activity**
Nurse-led pathway[19]	Assessment	Nurse (Band 7)	90	£120[20].	£180
	Discussion of diagnosis	Nurse (Band 7)	60	£120	£120
	Total cost (where no medication is prescribed)				**£300**
	If medication is prescribed (three reviews over six months):				
	Medication review 1	Nurse (Band 7)	30	£120	£60
	Medication review 2	Nurse (Band 7)	30	£120	£60
	Medication review 3	Nurse (Band 7)	60	£120	£120
	Total cost (where medication is prescribed)				**£540**
GP-led (old model)	Assessment	GP	90	£255[21]	£382.50
	Discussion of diagnosis	GP	60	£255	£255
	Outpatient appointment	Consultant Physician	N/A		£85

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[19] Some cases that are more complex still must be sent for specialist scans or neurological assessments in Aberdeen as before, and the costs of this are not included in these calculations.

[20] Personal Social Services Research Unit (PSSRU): Unit Costs of Health and Social Care 2020

[21] Personal Social Services Research Unit (PSSRU): Unit Costs of Health and Social Care 2020

Model	Activity	Professional (and band if relevant)	Time on activity (mins)	Cost per hour	Cost per activity
	Total cost (where no medication is prescribed)				**£637.50**
	Outpatient appointment with a consultant physician (assuming this is required in half of cases at £85 per appointment[22])				£42.50
	Total cost (where no medication is prescribed and an appointment with a consultant physician is required)				***£680***
	If medication is prescribed (three reviews over six months):				
	Medication review 1	GP	30	£255	£127.50
	Medication review 2	GP	30	£255	£127.50
	Medication review 3	GP	60	£255	£255
	Total cost (where medication is prescribed)				**£1,147.50**
	Outpatient appointment with a consultant physician (assuming this is required in half of cases at £85 per appointment[23])				£42.50
	Total cost (where medication is prescribed and an appointment with a consultant physician is required)				***£1,190***

To calculate the cost of diagnosis before the introduction of the nurse-led pathway, we have had to make some assumptions in the absence of detail on the number of appointments and time to reach diagnosis. We have assumed that:

- diagnosis was predominantly through a GP but in half of cases also required an outpatient appointment with a consultant physician
- GPs took the same amount of time (although possibly spread over more appointments) as the nurse in the nurse-led pathway to complete assessments and follow ups.

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[22] The cost of an outpatient appointment (not specialist specific) at the Gilbert Bain Hospital in Lerwick in 2019-20 was £85 - ISD Scotland. https://beta.isdscotland.org/topics/finance/file-listings-fy-2019-to-2020/ (accessed 14 June 2021)

[23] The cost of an outpatient appointment (not specialist specific) at the Gilbert Bain Hospital in Lerwick in 2019-20 was £85 - ISD Scotland. https://beta.isdscotland.org/topics/finance/file-listings-fy-2019-to-2020/ (accessed 14 June 2021)

The estimated costs do not include financial savings (travel, escort, overnight stay) from people not having to travel off island for assessment, as was the case in the previous diagnostic model, and so will be an underestimate.

The diagram below illustrates the estimated savings per patient per diagnosis in the nurse-led pathway based on the calculations laid out in Table 5.1.

Figure 5.4: Summary of savings per diagnosis and estimated savings based on total diagnosis in 2019.

Evaluating the Shetland site

As described in Chapter 2, initial conversations with the innovation site team in Shetland and reviews of documentation like the driver diagrams and project outcomes informed the evaluation plan for the project and the key outcomes were to:

- increase PDS uptake
- improve the experience of PDS for people with dementia and carers
- improve awareness of support services for people with dementia among primary care staff
- reduce the need for GP support among people with dementia and carers.

Table 5.2 summarises the breakdown of the contributors and table 5.3 provides the details of the local staff and stakeholders.

Table 5.2: Evaluation participants in Shetland

Project managers/ PDS staff	Local partners/ collaborators	People with dementia	Carers	Carer postcard responses	Health and social care survey responses
3	7	1	4	8	3

Table 5.3: Local staff and stakeholders

Project managers/PDS staff	Local partners/collaborators
Community Psychiatric Nurse, NHS Shetland (Project Manager)	Cluster Quality Lead, NHS Shetland Primary Care Manager, NHS Shetland

Project managers/PDS staff	Local partners/collaborators
Senior Practitioner, Community Occupational Therapy, Shetland Islands Council (Project Manager) Dementia Support Practitioner, Shetland Health & Social Care Partnership	Occupational Therapy Team Leader, NHS Shetland/Shetland Islands Council Dementia Advisor, Alzheimer Scotland GP Alzheimer Scotland Advanced Clinical Nurse Specialist, NHS Shetland Consultant, Older Adult Psychiatry, NHS Grampian Improvement Advisor – HIS[24]

The interviews with project staff, GPs, local stakeholders and service users, the workbook data, carer postcard responses and the health and social care staff survey responses inform the next section, which describes the impact of the pilot project.

Impact of the pilot project

In this section, we discuss the impact of the project on:

- people with dementia and their carers
- access to and uptake of PDS
- quality of PDS
- other services supporting people with dementia and their carers.

Improved experience of PDS

Evidence collected through the evaluation indicates that the DSP resulted in an improved experience of PDS for people with dementia and carers. This included effective practical support and advice to live well with dementia, liaison and collaboration with other services, support to plan for the future, reduced stress and anxiety, and support for carers.

Practical support and advice to live well with dementia

Evaluation participants reported that the DSP provided valuable and individualised practical support and advice to help people with dementia and carers to live well with the condition. Interviewees commented favourably about the DSP's *"person-centred"* approach which involved talking to people with dementia and carers about the challenges they were facing and suggesting solutions tailored to the needs of the family involved. Interviewees also spoke about the value and importance of the consistent and continuous support provided by the DSP.

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[24] This interviewee was not included in the numbers in Table 5.2 because she was interviewed twice as the Improvement Advisor and as a national stakeholder.

This was wide-ranging and included support to help people maintain their independence for as long as possible. This covered advice and suggestions on aids and adaptations to assist daily living such as dementia friendly clocks and signage, establishing daily routines and communication techniques, as well as support to apply for financial benefits such as council tax reductions. The DSP also discussed other services that could help the service user, and made referrals to arrange access to these services. These included third sector social activities, care at home services, and other health and social care services such as home based memory rehabilitation.

Liaison and collaboration with other services

The DSP also kept in regular contact with other support services involved with service users in order to share information that could inform the person's care. For example, in one case a person with dementia reported some side effects from their dementia medication to the DSP, so the DSP contacted the DAS on their behalf and this resulted in the person's dosage being modified. In another case, the DSP carried out a joint visit with a pharmacist to talk to the service user about strategies to ensure they took their medication at the right time.

Service users appreciated the co-ordination and linking role that the DSP played. One carer, for example, commented that it was beneficial to have the DSP acting as an intermediary with other services, and to have her as a single point of contact to discuss her mother's care.

Support to plan for the future

Another element of support that the DSP provided included helping people to complete anticipatory care plans. This helped people living with dementia and carers to anticipate how their needs would change as the condition progressed. The DSP suggested measures to pre-empt and adapt to these.

Reduced stress and anxiety

There wass anecdotal evidence to suggest that the DSP's support, and the knowledge that the DSP was available to help, contributed to reduction in stress and anxiety around living with the condition among service users. Carers in particular reported that the support provided them with *"peace of mind",* and described it as *"reassuring"*. One carer said the support *"took a lot of the stress out"* of the situation and a health professional noted that the role *"takes the strain off the relatives"*. A GP described the support as *"comforting"* for people living with dementia and carers, helping to make:

> *"Their situations feel a bit more bearable knowing that that sort of support is available."*

And a carer commented:

> *"It is so reassuring to have [the DSP and DAS] as a point of contact in my husband's dementia journey."*

IVY'S STORY

Ivy was diagnosed with Alzheimer's in her eighties. She had lived alone since her husband died in the 1980s, but found she was getting forgetful and struggling to live independently so moved in with her son Greg and his wife.

The DSP became involved to support both Ivy and Greg.

CASE STUDY SHETLAND

CARER SUPPORT

- The DSP supported Greg with issues around his new role as a carer for his Mum. Part of this was an online course about dementia run by the University of Stirling.
- The DSP helped to arrange respite care to give Greg and his wife a break.

PEER SUPPORT

- Ivy attended respite care. Her son noted that, 'she had a whale of a time' on these occasions.

PLANNING AHEAD

- The DSP provided practical tips and advice on everyday care.
- The DSP was able to advise about hygiene and incontinence issues.
- The family and DSP keep in regular contact through phone calls and emails to talk about ongoing issues.

LIVING WITH DEMENTIA

- The DSP explained dementia to Greg to help him understand what was happening to his Mum.
- The DSP helped Greg navigate to relevant information about dementia. Greg was very positive about their support.

"The team are there for us as we go through it. In a recent crisis the DSP took a lot of the stress out of it... we knew someone was there and she gave us good advice."
GREG

"The DSP helped me deal with the emotional and mental challenges of being a carer and to prepare and understand [dementia] a bit better."
GREG

Support for carers

The DSP's role also involved supporting the carers with their own needs. There are examples of where the DSP had one-to-one meetings with the carer to discuss their needs and the impact of the caring role on their wellbeing. For instance, the DSP suggested some podcasts and literature and provided signposting to other services for one carer who was having mental health issues. Some evaluation participants noted that this kind of support helped to reduce the burden on carers. A health professional observed that the DSP:

"Has really helped carers feel supported and like they have someone to speak to that understands. This is a massive help." A carer said the DSP "was easy to talk to and I felt better."

Access to and uptake of PDS

The introduction of the DSP role helped to improve the pathway linking people diagnosed with dementia into PDS. The DSP worked closely, and was co-located, with the DAS team. All assessments and diagnoses on Shetland were carried out by the DAS. This close working relationship meant there was a clear and seamless link to PDS for everyone diagnosed with dementia, something that was missing in the old model. This ensured that everyone who received a dementia diagnosis was referred to PDS. Evidence provided in the workbooks suggest that all 154 people diagnosed over the period by the DAS since the DSP was appointed were referred for PDS.

Percentage of people diagnosed with dementia referred for PDS:

100%

78%

survey respondents aware of the DSP felt the role had enhanced awareness of PDS services **and** how to access them among people living with dementia with carers

Evaluation participants reported that this simplified pathway enhanced awareness of PDS services and improved knowledge of how to access PDS among people with dementia and their carers.[25]

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[25] We received 16 responses to our survey of GPs and primary care staff in Shetland. Eight were GPs and eight were AHPs. Seven of the eight GPs who responded were not aware of the DSP. This was an issue that we discuss later in this chapter. These respondents were unable to comment on the DSP's role because they were not aware of it, so where we present quantitative results from this survey in this chapter, we have limited it to responses from the nine respondents (eight AHPs and one GP), who were aware of the DSP and her work, unless otherwise stated.

In terms of take up of PDS, workbook data shows that 129 (84%) of the 154 people diagnosed with dementia and referred to the DSP took up the offer of PDS. This was a substantial increase of 44 percentage points compared with the 40% who took up PDS before the DSP was appointed, as reported by the site, when PDS was delivered by social care staff as part of their wider role.

The data collected by the site shows improvements in the time between the referral for PDS to the date of first contact with the DSP. This reduced from 179 days in 2017 to 23 days in 2019.[26] Similarly, the time from diagnosis of dementia to referral for PDS decreased, from 169 days in 2017 to 12 days in 2021.

Figure 5.5: Reduction in diagnosis to referral and referral to first contact times.

Consistency and quality of PDS

This model also promoted the delivery of consistently high quality PDS. This was not always the case under the old model, when the quality of provision depended largely on the time that each individual worker had to devote to PDS amidst their heavy workload, and when there was a lack of co-ordination and no clear responsibility for ensuring that PDS was delivered. The DSP role provided more structure, with DAS taking responsibility for making referrals and the DSP role ensuring that PDS was delivered by a practitioner dedicated to the role and with the time and relevant skills and experience to deliver high quality PDS.

Stakeholders who took part in the evaluation were very positive about the impact of the DSP role on the quality of PDS available in Shetland, as the following comments illustrate:

> *“A much more effective way of supporting the clients and carers”* (AHP)

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[26] We have used 2019 data for this calculation because the COVID-19 pandemic and the DSP’s maternity leave meant there was a significant decline in first contacts in 2020.

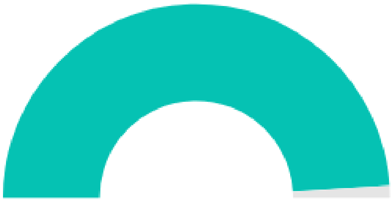
> *"Prior to [the DSP] being in post, there was a real gap in service with no real pathway to support people living with dementia and their family and carers. The Dementia Support Practitioner role has completely changed that and made an incredible difference in the support available to people living with dementia, their families and professionals."* (AHP)

Impact on other services that support people living with dementia and carers

Enhanced awareness and knowledge of dementia care and support

Professionals who took part in the evaluation reported that the DSP role helped to enhance their awareness and knowledge of diagnosis and PDS services available in Shetland.

Figure 5.6: Increase in awareness and knowledge of diagnosis and PDS services available in Shetland.



98%

survey respondents aware of the DSP had improved
knowledge of dementia diagnosis pathway
and awareness of PDS services

One AHP noted that the DSP:

> *"Has been very clear in her role and has really helped me understand the route for diagnosis plus what support is available following a diagnosis."*

We should note, however, that seven of the eight GP survey respondents stated that they were not aware of the DSP role. A few other stakeholders also noted that this lack of awareness among GPs was an issue with the role, and we discuss this further later in this chapter.

Improved knowledge and skills for supporting people living with dementia and carers

Another theme that emerged through the interviews and survey with health and social care professionals was the positive impact that the DSP had on their knowledge and skills in supporting people with dementia and their carers. The DSP did not deliver any formal training but evaluation participants noted that through collaborative working, discussing cases at team meetings and acting as an informal sounding board on issues related to dementia, the DSP improved other professionals' ability to support people with dementia and carers.

Survey responses show that nine respondents agreed that the DSP helped to increase the respondents' awareness of the needs of patients the DSP has supported, and six (67%) felt the role improved their confidence in supporting people with dementia and carers. Comments from survey respondents include the following:

> *“I worked alongside her in the office which allowed me to better understand her role, I was able to ask for advice and guidance to help me support those with dementia. I developed my knowledge re dementia as we often discussed cases and scenarios and she could give me reasons as to why a person was perhaps displaying certain characteristics (mainly due to type of dementia) and I was able to tailor my support to a person due to this improved knowledge” (AHP)*

> *“[The DSP] has been such an asset in this job and I really appreciate the collaborative approach that she takes. This has significantly advanced my own knowledge of dementia and how we support clients and carers in Shetland” (AHP)*

Again, however, we should note that the apparent lack of awareness among GPs has limited the DSP’s impact on this group of professionals, and we return to this issue later in this chapter.

Greater efficiencies across services

This evaluation has collected some qualitative evidence that the DSP role helped other health and social care services to achieve greater efficiencies. Some interviewees, including AHPs and GPs, explained that the DSP’s focus on the social, emotional and practical aspects of living with dementia means that GPs and AHPs do not have to discuss these issues with service users as much as before, thereby saving them time and enabling them to focus more on the clinical needs of the person with dementia. Some interviewees reported that, although the role has not led to any reduction in appointments with GPs and AHPs, it reduced the length of appointments.

For example, an Occupational Therapist noted that:

> *“Referrals we get now are more effectively triaged. Our role takes less time because the DSP covers social, emotional and informational support, so we can concentrate on the OT role.”*

Some GPs that we spoke to mentioned that it was difficult to disentangle the work of the DAS from that of the DSP from their perspective. They explained that the establishment of the DAS reduced the pressure on them in terms of diagnosis and support for people with dementia, and they saw the DSP’s role as augmenting this. One said that that DAS service as a whole:

> *“Is soaking up a lot that would otherwise come to us.”*

LYDIA'S STORY

Lydia was diagnosed with dementia in her early sixties. Her colleagues had noticed deterioration in her memory and suggested she investigate.

She was upset by her diagnosis, especially as it meant giving up work and driving. She became wary of using electrical items in case she had an accident, which limited her ability to carry out daily tasks independently. She sometimes had difficultly finishing sentences.

Lydia initially declined PDS but later contacted the DSP for support. Lydia lives with her husband Derek, who has also received support as a carer.

CASE STUDY SHETLAND

CARER SUPPORT

- After a carer support assessment Derek was referred to social work and Voluntary Action Shetland for help.
- The DSP also recommended resources he could access about being a main carer.

PEER SUPPORT

- The DSP suggested other services that could help Lydia, such as a dementia cafe.

PLANNING AHEAD

- Lydia completed a Getting to Know Me form and ACP.
- Lydia was one of the first people in Shetland to receive HBMR.
- The DSP helped Lydia resolve issues with her medication and suggested contacting Alzheimer Scotland for future support.

LIVING WITH DEMENTIA

- The DSP suggested signage to help overcome fears of using household applicances and a dementia-friendly phone.
- She also gave reassurance and advice on planning a 'bucket-list' dementia-friendly holiday.

"You're completely in the dark when things like this happen...you don't know how to approach things...lots of things you don't understand. But our DSP helped us and gave us advice on how to live with dementia."

DEREK

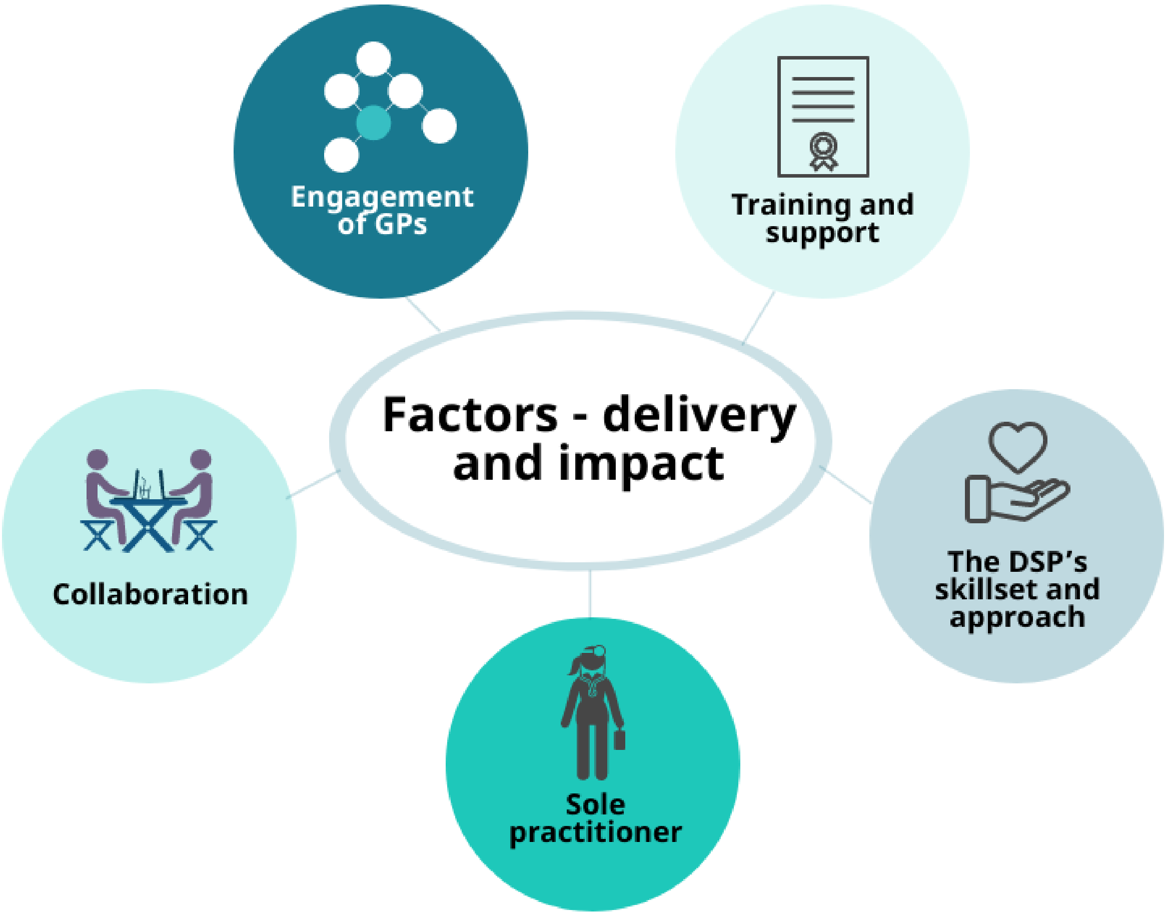
"Our DSP had a very professional and friendly approach. She was easy to talk to and you could talk plainly to her."

DEREK

Learning, enablers, and barriers

In this section, we describe learning points from the implementation of the DSP role in Shetland, including factors that have contributed to the success of the role, as well as barriers and enablers.

Figure 5.7: Shetland – factors affecting delivery and impact



Engagement of GPs

There appears to be a lack of awareness of the DSP role among some GPs. While interviewees and survey respondents, including some GPs, who were aware of the role were positive about it, many (including seven survey respondents, 44%) were not aware of the role:

> *"This is the first I've heard of the dementia support practitioner" (GP)*
>
> *"To the best of our knowledge she has not had any interaction with any of our patients. Neither I, nor the practice has had any contact with her" (GP)*

Stakeholder interviewees felt the DSP and her line Manager had tried hard to build engagement among GPs but with little success. The reasons for this are unclear but stakeholders felt it could be due to GP turnover, locum cover and GPs' workload generally affecting their ability to read or respond to communications such as the leaflet outlining the DSP role that was produced and circulated to GP practices.

GPs seemed to be more aware of the DAS team and identified them as their main source of support for people with dementia. In this way, GPs were indirectly linked to the DSP in that any relevant queries would be passed on to the DSP by the DAS.

However, it would be beneficial for the DSP to have a greater profile among GPs, and this was identified by interviewees as an area where the role could be enhanced. This would allow the DSP to:

- contact the GP if they observed anything in their work with a service user that required GP intervention
- provide informal updates to the GP on the service user like insights into the person's circumstances at home that could inform decisions around future treatment
- act as the main point of contact for GPs who had any queries or requests related to a patient's PDS.

Comments from evaluation participants included the following.

> *"Inform GPs that this person is in post, what their role is and how GP can contact them." (GP)*
>
> *"Better communication with primary care, both GPs and nurses, of what services the dementia support practitioner provides [would be helpful]" (GP)*

Training and support

While the DSP had existing skills and experience, the DSP and other stakeholders noted the value of learning materials related to dementia provided by HIS, most notably resources created by NES.

However, a few interviewees noted the need for more consistent and standardised training and continuous professional development for PDS practitioners across Scotland.

HIS gave support that went beyond provision of training materials, and the project team commented favourably about this. The Focus on Dementia team at HIS was seen as a valuable and trusted source of advice and the support throughout the project, including regular one-to-one meetings, was appreciated. An interviewee also noted that the HIS Quality Improvement Framework for PDS had been helpful in drawing up the job description for the DSP role and in benchmarking the service.

DSP's skillset and approach

Interviewees commented on the importance of the DSP's skillset. The postholder previously worked in both community nursing and social care so had a range of skills and experience that enhanced her ability to deliver effective PDS. One interviewee described the DSP as *"very effective".* Interviewees felt this skill mix was critical to the success of the role in Shetland.

In addition, evaluation participants who were aware of the DSP were universally positive about her approach to the role. The postholder was described as friendly and service users appreciated this approach, as the following comments illustrate:

> *"[The DSP] gave helpful suggestions and practical help, was very friendly and reassuring" (carer)*
>
> *"[The DSP has] been very helpful, open and friendly" (person with dementia)*

Sole practitioner

One of the main challenges involved with the implementation of the role in Shetland was the DSP's status as a sole practitioner, with nobody else dedicated to delivering PDS in Shetland. This meant there was no cover for the DSP if she was ill, on leave or unavailable for another reason.

This issue was highlighted when the DSP went on maternity leave in February 2020. This coincided with the COVID-19 outbreak and pressures caused by the COVID-19 pandemic meant that it was not possible to recruit anyone to cover the role. As a result, delivery of PDS was added to the DAS team's responsibilities while the DSP was on leave. While there was no evidence of this having any adverse effect on service users, it did add to the DAS's already heavy workload. It may be beneficial to consider ways in which the DSP's role could be more effectively covered in her absence, and this was an important learning point for Shetland and other areas where responsibility for PDS lies with a sole practitioner.

Collaboration

A recurring theme that emerged through our evaluation was the importance of the DSP's close collaborative working with other services. As noted above, this helped to improve other services' skills and knowledge in supporting people with dementia and their carers. Interviewees felt that this benefitted service users because it enabled sharing of knowledge and skills, and collaboration on individual cases to ensure the person was receiving the most appropriate care.

For example, the DSP was located in the same building as the social work team, allowing *"constant interchange"* between the teams and regular discussion of cases – an interviewee said the DSP role *"dovetails really well with adult social work"*.

Interviewees also reported good collaboration between the DSP and Alzheimer Scotland, with close joint working and complementary support delivered on shared cases.

Co-location with the DAS team

The DAS team noted that the DSP role *"dovetails"* with their service too. They felt the DSP role enhanced the DAS service, allowing the assessment staff to focus on the clinical side of diagnoses, while the DSP deals with social and practical issues. This staff member commented that the DSP role:

> *"Makes [the DAS] a more holistic model."*

The team commented that collaboration with the DSP became easier when the DSP moved to the DAS office. Previously she was located in the Occupational Therapy office, around four miles away.

Sustainability and spread

Evaluation participants, when aware of the DSP, were very positive about the role and the impact it had on people with dementia, carers and other health and social care services in Shetland.

The post was mainstreamed and made permanent with funding from Shetland HSCP in 2020 and will be sustained for the foreseeable future. Evaluation participants were supportive of this development, but some noted the need to expand capacity to further enhance the impact of the role and to reduce the issues around the DSP being a sole practitioner:

> *"Having seen this role first-hand and the demand upon her I can only suggest there are more of these roles developed, they do not only help families but also us professionals" (AHP)*

> *"We could do with more feet on the ground to meet increasing demand... [the DSP is] spread pretty thinly" (GP)*

Whilst the DSP role has been mainstreamed, the future of the wider DAS team was uncertain which could impact on the sustainability of the DSP role. One of the two nurses was semi-retired but was continuing to lead the service and the other left his post earlier this year. While the team was being supported by a nurse from the adult mental health team, uncertainty around the capacity and future of the team remained.

Summary

Overall, the Shetland innovation site was a success. 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 have to wait for PDS.

There was also evidence of improved experience of PDS among people with dementia and carers, with PDS delivered in a more structured and consistent way than before. Interviewees 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.

The DSP also had a significant impact on other services. In some cases, professionals in other services reported being more aware of dementia diagnosis and PDS services, and there were also examples 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 AHPs, to achieve greater efficiencies with their time. While there was no quantitative evidence of this, some interviewees reported that the DSP’s role helped to reduce the length of appointments that GPs and AHPs had with people with dementia.

The factors that supported the success of the project included close collaborative working with other services, co-location with the DAS team and the DSP’s personal skillset and approach. Challenges have included the DSP’s sole practitioner status, which affected continuity of support if the postholder was absent for any reason, a lack of engagement from some GPs, and uncertainty around the future of the wider DAS service.

Despite these challenges, it was encouraging that the post was mainstreamed and sustained with funding from the HSCP, and this should help to continue the positive impact that the DSP has had so far.

6. Discussion and considerations

The three innovation sites pursued different approaches to testing the relocation of PDS within primary care hubs. 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 for how PDS could move to, and the benefits of, a primary care model.

The evaluation across the three sites sought to answer some key questions, which are discussed in the rest of this chapter.

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. In Shetland diagnosis was followed by a seamless referral on to PDS.

As a result of the services, in both Edinburgh and Shetland PDS was perceived to be more accessible.. 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, compared to national estimates.

From the comments of the evaluation participants, this provision has led to more opportunities to access PDS and a better quality experience. In Edinburgh , the service continued during the COVID-19 pandemic, which was a lifeline for many who faced isolation with so many services forced to close. By embracing technology and adapting the provision, PDS continued for patients in the cluster. A blended model for delivering PDS using some of these successful elements would be useful going forward.

Impact on primary care staff and primary care settings

Across the innovation sites dementia awareness training was delivered to practices and other training and support given on the diagnostic process from the Consultant Psychiatrist within the Focus on Dementia team. 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 patients 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 in 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 has 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 was 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.

The three innovation sites had the opportunity to share practice and learn from each other through the co-ordinating and supporting role of the Focus on Dementia team at learning events and knowledge exchanges. 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.

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. Any further roll out of the Edinburgh model, faces the challenge of finding GP clusters motivated and willing enough to fund and support the service.

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. That clarity made the messaging about the service and links to other complementary information and services easier for others to understand. 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. The DSF role was developed through proactive line management and also the team took a leading role in the steering group.

As with any service, staff changes can cause disruption and this was the experience for all three, 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 clinics. Connection with GP systems was key to co-ordinating care and the 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 Dementia Support 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, with feedback noting their ability to listen, reassure, encourage and identify practical and emotional solutions to supporting people to live well with dementia as well as connecting them to other support in their community. The importance of having the right person in this post was clear. If the right staff are to be retained, the responsibilities and workload should be graded at a level commensurate with the role and on a par with other dementia link workers.

Throughout the delivery period the innovation sites received **ongoing support** from the Focus on Dementia Improvement Advisor. Regular monitoring and reporting to this team, opportunities for collaboration, and this committed support were crucial in keeping the national programme on track and the sites engaged.

Costs and benefits

It has not been possible to explore the costs of this type of model compared with delivering this service in a more traditional setting for all three sites. The evidence and activity data needed to assign costs was either not collected or not accessible because of data ownership and restrictions.

However, costings of the diagnostic pathways in both Shetland (under the nurse-led model) and Nithsdale (under the dementia practitioner led model) showed the potential savings per diagnosis for these less traditional assessment pathways. With this indicative financial saving, along with effective and timely diagnosis, other localities should explore how their diagnostic pathways could adopt some of these elements to improve their PDS.

The innovation sites were funded by the Scottish Government and although Shetland has mainstreamed the role from within their HSCP budget, the Edinburgh model operates on this short term funding. There is an opportunity to review this piecemeal approach and different funding sources for contracted PDS, community based support and the wider link worker programme across practices and then to explore the prospects and added value in existing resources to better link in with a primary care model.

Consideration should be given to working with those who deliver PDS to undertake a comprehensive cost consequence analysis of the various models of delivery in order to fully understand the costs and benefits of the service and any financial efficiencies. This would provide the business case for funding from other sources, for example primary care, if a quantifiable decrease of GP time and resources was evidenced. It would also help inform future commissioning decisions about the type, delivery model and cost of PDS.

Spread and sustainability

In Shetland the diagnostic pathway and onward post diagnostic support was the established route for dementia care and support. Whilst still reliant on key individuals, it was embedded within the system and for its continued success now needs further promotion and awareness-raising amongst primary care. This would help GPs gain a better understanding of the PDS element of the pathway.

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 intended roll out across the region will lead to significant changes in the timeliness and access to dementia diagnoses.

The service in East Edinburgh will hopefully influence the wider picture of support across the city but the consolidation and further roll out would require significant engagement of GPs, overcoming the logistical challenges of working within a cluster (including access to GP IT systems), project management support and identifying sources of funding.

Over the last four years the learning from these differing approaches has been shared by the sites and more widely by the Focus on Dementia team. Networks and learning systems, delivery group meetings, National Dementia PDS Leads Meetings, newsletters, webinars, flash reports and NHS and Alzheimer Scotland events had all been vehicles for exchanging insight and information. This report adds a further perspective and looks at the successes and challenges from the services delivered in the three areas.

Conclusion

The innovation sites delivered their services during 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 the dementia journey and should be considered by those looking to improve the quality and experience of dementia care and support. Service deliverers and commissioners should reflect on:

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

Appendix 1: Additional case studies

ROB'S STORY

Rob was in his mid-70s when he received a dementia diagnosis.

He lives with his wife, Michelle, and daughter, Fiona. At the time of his referral, he was concerned that he would be unable to maintain his interests and hobbies including fencing, travelling and involvement with community groups.

Michelle was working full time, so Rob was on his own during the day. He mood was low, which had a negative impact on his relationship with Michelle and Fiona. He also has a heart condition.

When Rob's condition deteriorated, Michelle retired to care for him.

CASE STUDY SHETLAND

CARER SUPPORT

- The DSP met with Michelle at work to discuss her caring role.

PEER SUPPORT

- The DSP provided information about a local dementia café and persuaded Rob to attend.
- She also explained the support services and activities that were available in Shetland.

PLANNING AHEAD

- Help to complete paperwork to access health and social care services.
- Provided information about relationship counselling services.
- Referral to audiology to explore hearing issues.
- Referral to Home Based Memory Rehab service.
- Discussed coping strategies and plans for future care before DSP’s final visit.

LIVING WITH DEMENTIA

- DSP gave advice about signage in the house to help Rob find things.
- Suggested Rob should write a daily gratitude journal to highlight the positive aspects of his life.

"The DSP gave us information I don't think we would have found without her. She was a great help and her support was therapeutic."
ROB

"I got on really well with her and looked forward to her coming."
ROB

CASE STUDY EDINBURGH

LIZ'S STORY

Liz was in her early 70s when she started to experience mild cognitive impairment (MCI) while she was still working. She was referred to a DSF for support by her GP. She was encouraged to retire and return to work as a volunteer. However her condition deteriorated further and she retired completely. She was then diagnosed with Alzheimer's.

Liz has a history of depression and shielded during the pandemic due to asthma. Brian, her partner of nearly 30 years, has his own mental health issues but is very supportive.

One of the difficulties caused by the MCI and Alzheimer's was that Liz started to confuse Brian with her grandfather or her previous husband. The latter was traumatic because this had been an unhappy relationship.

CARER SUPPORT

- The DSF helped Brian with the carers assessment form. He was allocated a support worker as a result.

PLANNING AHEAD

- The couple established POA.
- The DSF liaised with other services such as the Memory Clinic and the couple's GP.
- The DSF supported Liz through problems with her memory medication.
- The DSF initiated contact with the dementia dogs service.
- She also helped Liz and Brian organise an Attendance Allowance and Council Tax reduction.

PEER SUPPORT

- The DSF referred Liz to Movement for Memories, but this stopped with the first Covid-19 lockdown.
- She also suggested community activities in line with the couple's interests, including a singing group.

LIVING WITH DEMENTIA

- The DSF made practical suggestions for Liz to keep her busy and occupied. She is knitting soft toys to raise money for the NHS – this gives her something to focus on, provides *"solace and comfort"* and helps to *"maintain skills"*.
- She also adviced on signage in their house.

"The DSF helped us find a community of people going through similar experiences. It's really helpful to be able to share what we're going through with them."
LIZ

"It was distressing to become a carer not a partner. Our DSF was there for me too...she was a listening ear...she helped me get more support."
BRIAN

HUGH'S STORY

Hugh was diagnosed with Alzheimer's in his late eighties. A retired tradesperson, he lives with his wife June.

Hugh had always been an active person, playing bowls and golf and running marathons. He always liked to be busy and occupied. This proved particularly challenging during lockdown, when June found it difficult to find activities around the house to engage him.

The DSF started working with the couple in December 2019, shortly after their daughter had died of cancer.

CASE STUDY
EDINBURGH

CARER SUPPORT

- The DSF signposted Hugh and June to the Edinburgh Carer Support Team. They arranged a grant to pay for taxis so June could visit her grand-daughter every week.

PEER SUPPORT

- The DSF gave Hugh information about activities like the singing group at the Festival Theatre.
- The couple were invited to join the virtual support group being trialled by the DSF.

PLANNING AHEAD

- The DSF provided the couple with information about a Council Tax reduction and the Attendance Allowance.
- The DSF gave the couple information about Dementia Dogs and the Herbert Protocol.
- POA details were added to KIS.
- They were referred to outreach support (and eventually a day care centre).

LIVING WITH DEMENTIA

- The DSF provided the couple with information about signage and other visual aids for the house.
- The DSF referred Hugh to Movement for Memories and he was able to play golf again.

"The weekly visits from the day centre give me a two-hour respite. It's the only time I get to myself. I use the time to visit my grand-daughter."
JUNE

"We couldn't have done without [our DSF]...I know if there's anything not right I can phone her any time...she's very caring and supportive."
JUNE

VIOLET'S STORY

Violet was diagnosed with dementia in her early 80s. She was on medication for insomnia and anxiety. Her main carer was her sister, her only relative in Shetland, although her children checked in regularly.

Violet was determined to maintain her independence and to continue cooking, baking and cleaning. However, her children were concerned that she lacked insight into the impact of dementia, and worried that she was forgetting medication.

Violet's children asked for the DSP's support. The DSP visited Violet when she could, and kept in touch with the rest of her family.

CASE STUDY SHETLAND

PEER SUPPORT

- The DSP suggested Violet attend a tea dance hosted by Alzheimer Scotland. Although initially reluctant to go, Violet enjoyed the experience and started attending a dementia cafe as a result.
- The DSP introduced Violet to a befriending service - Violet got on well with her befriender.

CARER SUPPORT

- Violet's sister was too ill to care for her. The DSP persuaded them to have a care at home service to help them out.
- The DSP arranged help with shopping and a meals on wheels service five days a week.

PLANNING AHEAD

- The DSP completed an Anticipatory Care Plan with Violet's daughter.
- The DSP worked with Violet to draw up a person-centred outcome plan focused on maintaining independence.

LIVING WITH DEMENTIA

- The DSP gave advice on home safety, including providing safer alternatives to candles, the use of which had caused Violet's family some concern.
- The DSP and local pharmacist helped set up reminders for Violet to take her medication every day.

> "The DSP took a lot of stress out of the situation. It was so reassuring to know someone was there and could take over, as I don't live near my Mum."
>
> NADINE

> "Our DSP acted as a central point of contact... before she came along there wasn't one person I could discuss everything with."
>
> NADINE

ELSIE'S STORY

Elsie is in her early nineties and registered blind. She's been living alone since her sister moved into a care home in 2020.

Elsie was first diagnosed with MCI in May 2020. She sometimes forgot to eat and couldn't recall her carers visiting. Her condition progressed and she was diagnosed with Alzheimer's later the same year. She had problems living independently and had lost weight, partly as a result of not being able to see food in her cupboards and fridge.

Elsie moved into a care home at the end of 2020. The DSF had supported her right from her MCI diagnosis and continued to do so after her move. She also supported her family friends Jean and Simon who were very involved in Elsie's care.

CASE STUDY
EDINBURGH

PLANNING AHEAD

- The DSF provided Elsie with information about the Attendance Allowance.
- The DSF established a package of support for Elsie following her MCI diagnosis including PhoneLink and a referral to social work.
- The DSF helped draw up an emergency plan with key information to help if Jean and Simon were not there.

PEER SUPPORT

- The DSF referred Elsie to a befriending service.

LIVING WITH DEMENTIA

- The DSF gave advice on installing a community alarm and dementia-friendly clocks and signage to make Elsie's home safer.
- The DSF referred Elsie to her GP about her continued weight loss. The GP got Elsie help from a dietician.

SUPPORT IMPACT

- The DSF felt that the support provided helped to delay Elsie's admission into a care home by around six months.

> "We found it hard to get support from social services to start with, but the DSF co-ordinated things on our behalf."
>
> JEAN

> "We didn't know which doors to knock on... but [the DSF] had everything at her fingertips...you talk through problems and she helps"
>
> SIMON