Post-diagnostic Support in Primary Care: Progress report - October 2018 Innovation sites: East Edinburgh, Nithsdale (Dumfries and Galloway) and Shetland

Introduction

This paper summarises improvement work currently being undertaken in collaboration with Focus on Dementia and three GP clusters chosen to be innovation sites to test the delivery of dementia post-diagnostic support from GP practices. This work was commissioned by Scottish Government's Dementia Innovations Unit and is being led by Focus on Dementia the national improvement programme for dementia in Scotland based within the ihub of Healthcare Improvement Scotland. Focus on Dementia are working collaboratively with the appointed project managers in the clusters and with national partners including Alzheimer Scotland and NHS Education for Scotland. Clusters are typically groups of between five and eight GP practices in a close geographical location who collaborate on quality improvement activity with their peers and contribute to the development of their local healthcare system.

In January 2017 Focus on Dementia opened an application process to primary care via Integration Joint Boards who were invited to support GP clusters to apply to become innovation sites for dementia post-diagnostic support. We were delighted with the interest in this initiative and received ten applications, a higher number than anticipated. The Scottish Government identified additional funding to enable us to select three sites rather than the intended two. Applications were reviewed against criteria set by a selection panel and the three clusters were chosen based on clear evidence of having the necessary infrastructures in place to achieve maximum outcomes. In April 2017 East Edinburgh, Nithsdale and Shetland GP Clusters were announced as the innovation sites and received funding, a maximum of 50k per year to each site, for a period of two years.

Cluster details:

- Nithsdale cluster (Dumfries and Galloway) has nine GP practices working across 14 surgeries. The population is 59,217 people, of these 593 people currently have a diagnosis of dementia. The cluster is staffed by 37 GPs (approximately 32 WTE) with four vacancies. Three of the practices are training practices with a GP registrar in post. Each practice has their own Practice Manager, Admin Team and Practice Nurses. They are supported by an aligned team of District Nurses comprising 33 trained staff and 15 Healthcare Support Workers – six of the trained staff are Dementia Champions. In addition there are four (2.8 WTE) Prescribing Support Pharmacists who work in each practice on a regular basis.
- North East Edinburgh cluster has eight GP practices. The population in the East Edinburgh cluster is 57,724 people, of these currently 740 people have a diagnosis of dementia. The cluster is staffed by 11 GPs. The majority of the practices also have GPs at various stages of their training. They have between 0.7 and 3.4 whole time equivalent (WTE) practice nursing staff and between three and 11 WTE administration staff. All practices have

district nurse and health visiting teams although these are not always situated in the same buildings.

- Shetland cluster covers all of Shetland's ten GP practices. The population is 23,000, of these currently 170 people have a diagnosis of dementia. The practices range in size from 600 patients to 9,000 patients and there are 5 single handed practices, three of which are on islands reached by inter-island ferry and four practices that provide their own Out of Hours cover. GPs refer to a Nurse Manager, a Dementia Clinical Nurse Specialist (both full time) and a Consultant in Old Age Psychiatry at Royal Cornhill Hospital Aberdeen, who provides two sessions a week, who work together to undertake diagnosis of dementia in Shetland. Until the advent of becoming an innovation site Social Care Workers (6.2 WTE) from the Mental Health Community Support services endeavoured to carry out post-diagnostic support as part of their wider role.

Background to dementia post-diagnostic support in Scotland

In 2011, Alzheimer Scotland launched the 5 Pillars model of post-diagnostic support[1]. The purpose of post-diagnostic support is to equip people living with dementia, and those who care for them, with the tools, connections, resources and plans they need to live as well as possible and prepare for the future.

Since Scotland's second National Dementia Strategy[2] was published in April 2013, every person newly diagnosed with dementia is entitled to a minimum of a year's worth of post-diagnostic support from a named worker, including the building of a person-centred support plan. Scotland's third National Dementia Strategy[3] continues to emphasise the importance of prioritising the delivery and development of post-diagnostic support in Scotland.

Whilst we have made great strides with our dementia strategies there is still much to do to ensure post-diagnostic support is delivered at a consistently high quality throughout Scotland. We know from speaking to people with dementia, those who care for them, practitioners and other professionals, that current approaches to post-diagnostic support and the quality of post-diagnostic support services can vary greatly. The majority of post-diagnostic support practitioners are based within community mental health teams and diagnosis of dementia continues, with the exception of a few, to be made from psychiatry rather than primary care.

Dementia post-diagnostic support and primary care

As part of the Scottish Government's 2017-2020 National Dementia Strategy, it was proposed that the relocation of dementia post-diagnostic services into primary care be tested in three areas of Scotland hence the creation of this programme and the selection of Nithsdale, East Edinburgh and Shetland clusters. Part of the context for this is the modernisation of primary care agenda, with the expectation that even more focus is given within primary care to multi-disciplinary, comprehensive, person-centred and holistic condition management, especially for older people with frailty and co-morbidities and acknowledging that there are younger people with early-onset dementia. Added to this is the expectation that, over time, relocation into primary care would mean that post-diagnostic dementia services will become more accessible and "normalised" to individuals and families and that this in turn will encourage more people to come forward earlier for a dementia diagnosis or for a memory assessment.

The aims and objectives of the PDS in Primary Care programme are:

- To implement and evaluate the delivery of dementia post-diagnostic support from the three GP cluster sites (27 practices in total), engaging the wider primary care team, social work, housing and the voluntary and independent sector
- To understand which groups of individuals benefit from post-diagnostic support in primary care, demonstrating those benefits and the scope for delivery of improved outcomes
- To understand the distribution of need and demand for post-diagnostic support within the primary care setting
- To assess the cost and benefits of this approach to individuals and to health and social care systems.

Whilst the programme would not remove the need for referral into specialist diagnostic services in many cases, it is anticipated that once a diagnosis is confirmed, management of the individual's care and support will sit in primary care led by a dementia post-diagnostic support practitioner for an appropriate period. Having a practitioner located within the cluster, or closely affiliated with it, will also give GPs reassurance that, should they diagnose a patient or refer on for diagnosis, there are dementia post-diagnostic support services on hand to respond to the patient's needs after diagnosis.

In addition, it is anticipated that dementia post-diagnostic support practitioners would also have a role within a GP cluster in the areas of raising awareness about the service, pre-diagnostic work and taking forward innovative approaches such as primary care-based Memory Clinics and post-diagnostic support groupwork.

The anticipated benefits to the three GP Clusters becoming innovation sites include:

- Ensuring patients get quality care and support at the right place at the right time
- Access to dementia specific training from NHS Education for Scotland (NES)
- Support to test and evaluate this exciting, new approach of delivering post-diagnostic support from a primary care setting
- Direct access to a dedicated practitioner who has specific knowledge and expertise of dementia and post-diagnostic support
- Direct access to individual personal plans developed with the person and their family carers with support from the post-diagnostic support practitioner
- Encouraging closer links between primary care and specialist secondary mental health care services to ensure a timely and accurate diagnosis
- Access to dedicated funding to support this work
- Support with routine data collection and analysis
- Transferable knowledge, skills and experience that can be shared with colleagues locally and nationally.

The anticipated benefits to people with dementia, their families and carers of receiving post-diagnostic support from primary care include:

- Support being readily accessible from a local and familiar environment
- Support from staff who have a relevant understanding of dementia for the role they are in
- Access to a timely diagnosis
- Support to maintain community connections and peer support

- Support to develop a personal plan that helps with self-management and informs future care
- Support to make practical arrangements for the future.

How we got it going

Focus on Dementia dedicates the time of an Associate Improvement Advisor and Senior Project Officer to facilitate the programme. Prior to the aforementioned application process an interim Knowledge Exchange event was organised in February 2018 for interested parties from primary care to attend to hear more about post-diagnostic support (PDS), learn about the application process and share their expertise of primary care with Focus on Dementia. Within the initial application and selection process Focus on Dementia ensured each site had identified someone locally who had the skills and expertise, and who would be given dedicated time, to project manage the initiative and liaise with and report to Focus on Dementia on its implementation and progress.

To allow for a greater range of learning from the various aspects of delivery that best suited local contexts, the selected sites have been afforded the opportunity to innovate on how they approach the initiative.

NHS Education for Scotland (NES) and Alzheimer Scotland are key partners in the programme as members of the programme's Delivery Group (see reporting structure below) with NES also supporting the primary care site staff's dementia education requirements in relation to Scotland's Promoting Excellence framework[4]. Healthcare Improvement Scotland's Data Measurement and Business Intelligence (DMBI) unit also support the measurement aspect of the programme.

Our approach to improvement

Focus on Dementia applied the following quality improvement methodology and tools to the programme (see Appendix 1 for the overall programme Driver Diagram & key measures):

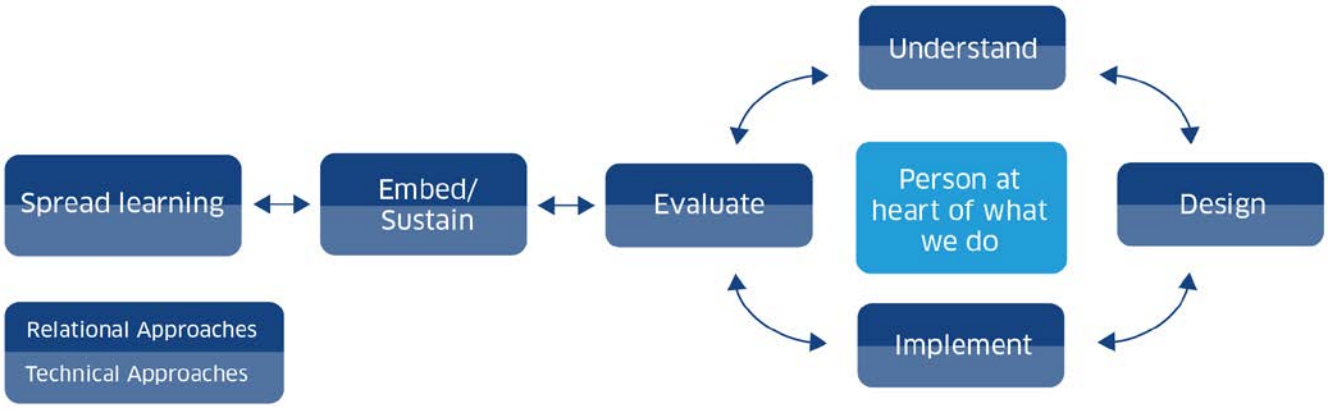
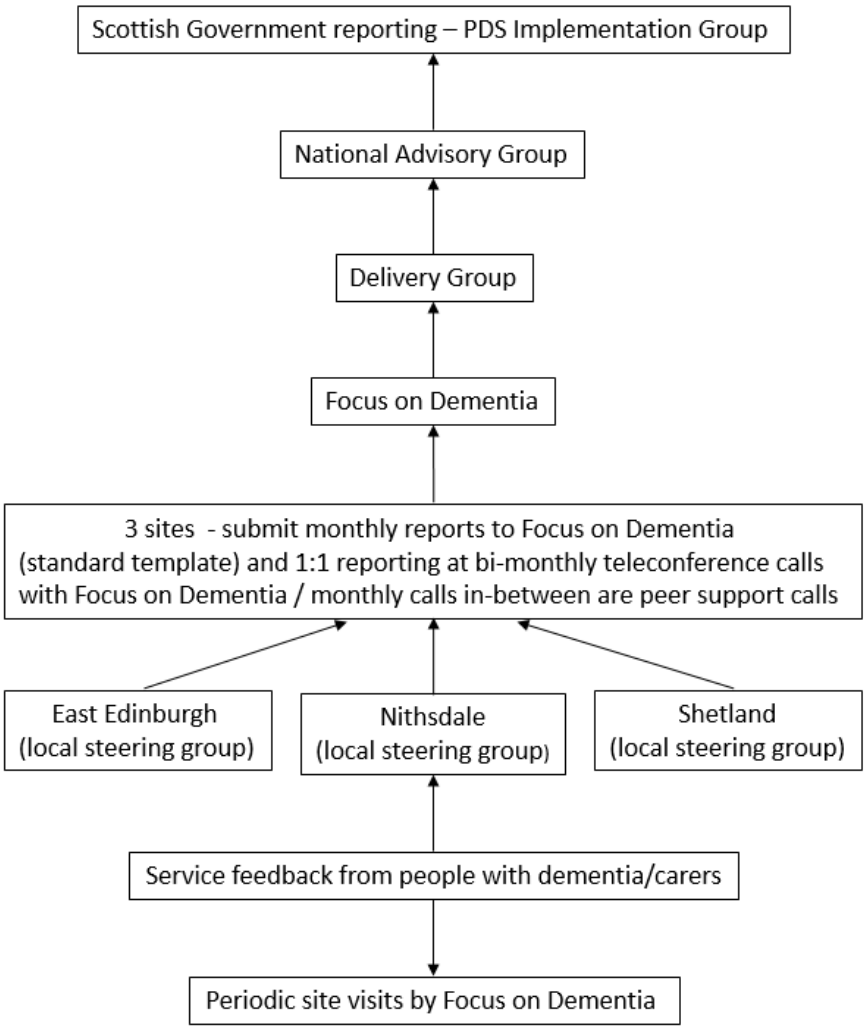


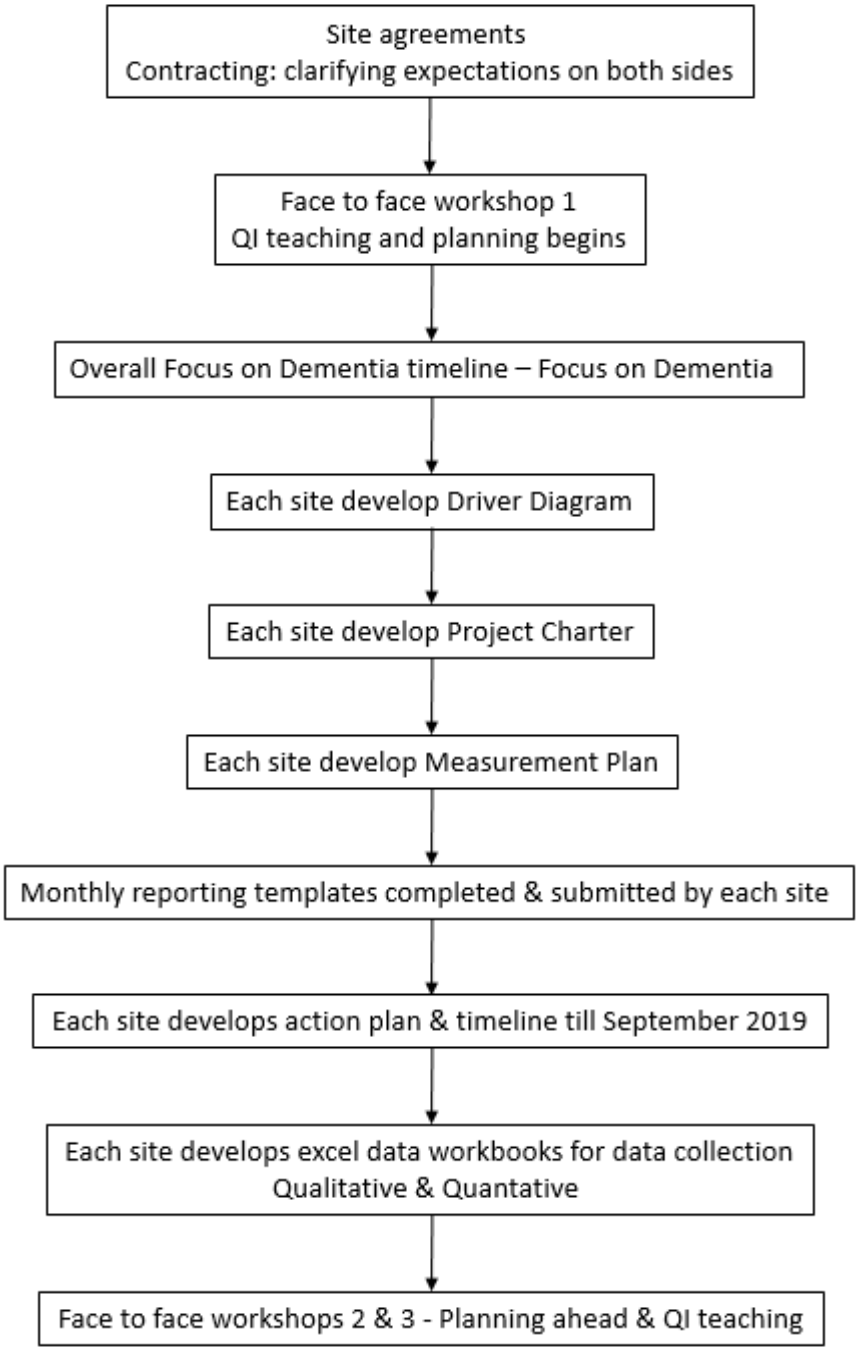
Figure 1: Healthcare Improvement Scotland - Framework for Planned Improvement

The structure for management, reporting and monitoring

Reporting structure applied to the programme



Quality Improvement tools applied to the programme



Enablers and barriers to implementation

The monthly report from sites detail progress and also capture enablers and barriers to progress. Here is a précis of enabler/barrier findings to date:

National Level - Using robust quality improvement (QI) methodology has been an enabler to the project. The Focus on Dementia Improvement Advisors are Scottish Improvement Leaders (ScIL) having undertaken the ScIL programme. Adopting tried and tested ScIL tools and templates into the programme has proved to be beneficial as it supports robust project management. In future more QI teaching will be built in at the beginning of programmes to ensure participating staff have the required knowledge and skills. Partnership working with NHS Education for Scotland (NES), Alzheimer Scotland, Information Services Division (ISD) and Scottish Government colleagues has been an enabler, bringing different perspectives and contributions. Sites being given some flexibility within the overall aim has proved to encourage innovation and local solutions to local needs whilst ensuring the overall scope of the programme is maintained.

In future it would be useful to ensure that sites are prepared for the amount of work and reporting that this type of work involves. Sites have reported that they were not especially prepared for this. A readiness for change is an enabler during test site work to ensure good buy-in of local stakeholders and an ability to complete the work in terms of their local resources. Sites need to have support for improvement and fundamentals such as staffing and leadership need to be in place and good site leadership infrastructure is essential to support the project managers.

The way in which the Focus on Dementia work is funded has been found to be a barrier generally as there is a lack of secured and long term funding. Two years for testing such an important area is not long enough, this is a finding of both the Focus on Dementia team and the sites themselves. Receiving money well into the financial year also impacts on the ability to plan. This can also lead to underspend in the sites and leads to difficulties at the end of the financial year. Recruitment of staff can prove challenging as it can take months to complete and impacts not only the timescales of the project but also the effectiveness. Change in personnel necessitates further time-consuming recruitment and the lack of a clinical lead GP from the outset of the programme was a barrier to local GP engagement.

Local level - The sites have reported that the professionalism and enthusiasm of the national team have been enablers. Building good rapport and open and clear methods of communication are essential. Face to face meetings with the sites and between the sites are a success factor and more site visits will be arranged going forward. Having a dedicated project manager with local knowledge is key as this individual is able to influence locally in order to be able to facilitate change. Part-time local lead hours can prove challenging for the individuals who report that engaging with multiple stakeholders can be frustrating and time-consuming. Local admin support has been identified as an enabler where present and a barrier when not. Peer support between the sites is crucial, preferably in the form of face-to-face meetings but also through other modes such as webinars, teleconferences and email. Project managers need to be supported via a leadership infrastructure and having a committed, local steering group has been identified as an enabler.

Summary of where sites are at one year in

East Edinburgh have appointed a full-time Dementia Support Facilitator called Oona who is attached to the cluster and primary care staff refer cases to her. Oona is providing one to one support for post-diagnostic support (PDS) and is helping to run PDS groupwork sessions too, two courses have taken place so far and have evaluated well, a third course is planned. Oona also receives referrals for people with mild cognitive impairment (MCI) where it is having an impact on daily living. Becki, the Project Manager for the initiative, is systematically working through the eight practices in the cluster to make sure they are fully engaged with the initiative, referrals to Oona are coming from six of the eight practices so far and she currently has a caseload of 34 people including six for MCI support.

Nithsdale main aim is to change the whole system of how people are diagnosed and have access to post-diagnostic support beginning with GPs diagnosing dementia for non-complex cases. They have tested Montreal Cognitive Assessment training on existing mental health staff and plan to roll this out to primary care staff. They also intend to run a PDS groupwork model. They have implemented a Friday morning clinic in Gillbrae, one of the GP Practices. This clinic has half-hourly appointments which GPs can refer people to for cognitive screening or for support if they are either worried about their memory, need PDS or general advice about dementia. They have a dementia information stand outside the clinic room and Michelle, the Occupational Therapy assistant who runs the clinic, can see people right away. Michelle has had 12 referrals from GPs so far and two from other practice staff. Some of the Nithsdale work was delayed as the original Project Manager left however a new manager, Amy, has now been appointed and took up post on 1 October 2018.

Shetland are using this initiative to overhaul the whole PDS service in Shetland. They have seconded a senior Occupational Therapist, Clare, to their programme two days a week and have also seconded Nikola, one of the existing Health and Social Care Workers, to work with Clare solely as a PDS worker 35 hours per week. Between them they are forging stronger links with the large health centres, Lerwick and Scalloway, and are now attending multi-disciplinary team meetings to promote the service and receive referrals. Clare has audited the existing service and is working on new processes including a new referral system for GPs to refer into PDS through the Occupational Therapy referral gateway. People who have previously declined PDS are being revisited and there's been better take up. Nikola, the PDS worker, currently has 24 referrals. They've also set some target timescales; five days from diagnosis to referral and 21 days from referral to first contact from Nikola.

Case study from East Edinburgh

Mrs A is 85 years old and has a diagnosis of Alzheimer's disease. She lived alone after her husband died until about a year ago when her son moved in as she needed his help and support. She has been gradually getting more and more stressed and distressed and there is a record of her setting fire to some papers in her flat. Her GP was very involved as the son would often phone the surgery asking for support when his mother would become suspicious or confrontational with him. The Dementia Support Facilitator (DSF) got in touch with her son who is her next of kin to ask if they would be keen on scheduling a meeting.

Mrs A was in good spirits during the meeting and very easy to talk to. She doesn't think anything is wrong with her memory and that is why she doesn't always take her medication. Mr A's son informed the DSF that they were visited by a Community Psychiatric Nurse (CPN) last week who is monitoring his mother's medication and has asked him to make sure she takes her tablets. He also said that his mother is struggling to get into her shower and he wonders if there are adjustments that can be made to make it easier for her. The DSF suggested getting in touch with Social Care in order to request an OT assessment on behalf of his mother. Both Mrs J and her son were happy with that.

After the meeting with Mrs A and her son it was clear that the situation was quite complicated. The DSF decided to get in touch with the CPN to inform her of the meeting that took place and the plan moving forward. The DSF also requested the OT assessment. The DSF met with Mrs A and her son for a second time to inform them that the OT assessment had been requested. Information about local groups and day centres that would be suitable for Mrs A was also provided. The CPN would be visiting Mrs A the next day in order to review her medication. Given that a CPN was already involved in Mrs A's care on a regular basis the DSF thought it was best to take a step back for the moment.

Mrs A's son had been contacting the GP regularly prior to any interventions taking place. Mrs A's GP has not received any calls since the referral to the DSF as would have been expected. The DSF has been in touch with Mrs A and her son over the phone to make sure they are doing okay. They received the letter with the details of the OT assessment. Mrs A's son knows he can get in touch with the DSF if he needs to. The DSF is planning to arrange a meeting with them again in about a month as Mrs A's son thinks this would be beneficial.

Additional benefits of the programme

Focus on Dementia have also been identifying opportunities to learn from other dementia in primary care initiatives such as collaborating with the Alzheimer's Society about their Dementia Friendly General Practice toolkit (DFGP) initiative[5]. The Alzheimer's Society generously shared information on this work with the clusters, and other interested parties from primary care, via a webinar on 29 November 2017. As a result of this liaison the Alzheimer's Society have agreed to share their toolkit with Alzheimer Scotland to support production of a Scottish version. This work is underway and will become an Alzheimer Scotland resource that will be more relevant and available to all Scottish GP practices. The three sites will be involved in testing the Scottish version before final publication.

Another collaboration has been with representatives of 'The Golden Ticket'[6] approach in East Sussex who presented a webinar for our sites and others on their highly successful dementia

initiative on 19 March 2018. This approach piloted by Buxted Medical Centre, is about working with a range of partner agencies to provide a co-ordinated package of support for people with dementia and their carers. It includes a primary care worker, medication reviews and a weekly clinic. Over 50 people tuned into this webinar.

Next steps

At the time of writing the PDS in Primary Care programme is halfway through its original duration however Focus on Dementia have confirmation of continued funding from Scottish Government to extend this work until end of March 2019 to allow for greater consolidation, data collection and spread of learning. The remaining time will focus on full implementation of change ideas, capturing the appropriate data and learning, informing the final evaluation and spreading this learning more widely.

Related work

Another Focus on Dementia led piece of work that relates to the overall improvement of post-diagnostic support in Scotland is the recent development of a Quality Improvement Framework for Dementia Post-diagnostic Support[7]. Developed in collaboration with PDS practitioners and by listening to people with dementia and carers' experiences, the framework identifies what a good PDS service looks like and helps services to make improvements in how they deliver support. A version for people with dementia and carers is also being produced.

References

1. Alzheimer Scotland 5 Pillars Model of Post-Diagnostic Support - https://www.alzscot.org/campaigning/five_pillars
2. Scotland's National Dementia Strategy 2013-2016 - https://www.gov.scot/Resource/0042/00423472.pdf
3. Scotland's National Dementia Strategy 2017-2020 - https://www.gov.scot/Resource/0052/00521773.pdf
4. Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers - https://www.gov.scot/resource/doc/350174/0117211.pdf
5. Alzheimer's Society Dementia friendly GP practices - https://www.alzheimers.org.uk/dementia-professionals/resources-gps/dementia-friendly-gp-practices
6. The Golden Ticket - https://www.health.org.uk/newsletter/golden-ticket-primary-care-takes-lead-improving-dementia-care
7. Quality Improvement Framework for Dementia Post-diagnostic Support - https://ihub.scot/focus-on-dementia/improving-diagnosis-and-post-diagnostic-support/quality-improvement-framework/

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Appendix 1

Overall programme Driver Diagram & key measures