Evaluation of the effectiveness of the "8 Pillars" model of home–based support

Final Report

Scottish Government

CONTENTS

APPENDICES:

1. Introduction

1.1 The Scottish Government commissioned Blake Stevenson to undertake an evaluation of the 8 Pillars home-based support model for people with dementia. The Scottish Government is working in partnership with QuEST, JIT, COSLA, ADSW and Alzheimer Scotland to test the '8 Pillars' Model developed by Alzheimer Scotland. The model recognises the importance of community support to provide an integrated approach to improving the resilience and independence of people with dementia and their carers, enabling them to live in the community for as long as possible.

1.2 The 8 Pillars model, described in the next paragraphs, sits within the overall context of Scotland's second national dementia strategy, 2013-2016, which focused attention on the following three challenges:

- to offer care and support to people with dementia and their families and carers in a way which promotes wellbeing and quality of life, protects their rights and respects their humanity;

- to continue to improve services and support from when someone presents for diagnosis, and throughout the course of the illness, including the support needs of carers. "This support must be truly person centred, and should understand care and support from their perspective, not the perspective of service managers or clinicians."; and,

- to recognise that with increased life expectancy the challenge of providing high quality care and support to people with dementia and their carers will increase over time. "We must embrace the process of redesign and transformation of services to ensure that we deliver services effectively and efficiently."

1.3 The strategy set out a number of commitments the third of which was as follows:

"Commitment 3: We will test and evaluate a range of approaches to providing better integrated care and support on the basis of the 8 Pillars model, centred on a Dementia Practice Coordinator role."

1.4 Alongside the national dementia strategy The BIG Lottery Fund established the Life Changes Trust in 2013, committed to investing £25 million over ten years (2013-2023) to improve the lives of people living with dementia. This has had an impact particularly in terms of supporting the development of dementia friendly communities.

8 Pillars Model

1.5 The 8 Pillars Model is a coordinated and strategic approach to providing effective, integrated community support to people with dementia and their carers. The model uses the strengths of health and social care to treat symptoms of the illness and improve the resilience of people with dementia and their carers supporting them to live in the community in a way that promotes their human rights. It isintended to be a preventive intervention and not as being mainly about crisis management. It recognises that for people to have maximum wellbeing both their health and social needs require attention.

1.6 The 8 Pillars of integrated community support developed by Alzheimer Scotland comprise:

- the Dementia Practice Co-ordinator;

- therapeutic interventions to tackle the symptoms of the illness;

- general health care and treatment;

- mental health care and treatment;

- personalised support;

- support for carers;

- environment-adaptations and aids to support the independence of the person with dementia and assist the carer; and,

- community connections-support to maintain social networks for both the person with dementia and the carer.

Dementia Practice Coordinator – a named, skilled practitioner who will lead the care, treatment and support for the person and their carer on an ongoing basis, coordinating access to all the pillars of support and ensuring effective intervention across health and social care

Therapeutic interventions to tackle symptoms of the illness – dementia-specific therapies to delay deterioration, enhance coping, maximise independence and improve quality of life.

Support for carers – a proactive approach to supporting people in the caring role and maintain the carer's own health and wellbeing.

General health care and treatment – regular and thorough review to maintain general wellbeing and physical health.

Personalised support – flexible and person-centred services to promote participation and independence.

Mental health care and treatment – access to psychiatric and psychological services to maintain mental health and wellbeing.

Environment – adaptations, aids, design changes and assistive technology to maintain the independence of the person and assist the carer.

Community connections – support to maintain and develop social networks and to benefit from peer support for both the person with dementia and the carer.

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1.7   The central component of the '8 pillars' model is the Dementia Practice Coordinator, a named, skilled practitioner already working within dementia care and at the Enhanced Level of the Promoting Excellence Framework such as community psychiatric nurses, social workers, and allied health professionals.

1.8   The Dementia Practice Coordinator identifies the individual needs of the person with dementia and their carer, supporting them on an on-going basis throughout their journey, coordinating access to each of the pillars and linking with the relevant practitioners and services to provide effective support and intervention across health and social care.

1.9   The 8 Pillars model sits alongside the 5 Pillars and Advanced Support models also produced by Alzheimer Scotland.

- Every person with a diagnosis of dementia in Scotland is entitled to one year of post-diagnostic support. The 5 Pillars model provides a framework for people with

dementia, their families and carers to allow them to live as well as possible and prepare for the future. The 5 Pillars are: supporting community connections; peer support; planning for future care; understanding the illness and managing symptoms; planning for future decision-making.

- In between the 5 Pillars and the 8 Pillars model, in the Alzheimer Scotland modelling, there is a period of supported self-management and it is only as the need for more specialist support emerges that the person will be offered the 8 Pillar support.

- The advanced dementia practice model proposes that each health and social care partnership area should have an Advanced Dementia Specialist Team (ADST) and that the Dementia Practice Co-ordinator role should facilitate the Advanced Dementia Specialist Team to enhance the care provided by the 8 Pillars team.[1] When a person has been assessed as requiring the Advanced Practice Model, the ADST will prepare a care plan that covers the person's physical, psychological and social care needs. The care plan will be held by the DPC and the 8 Pillars team.

The 8 Pillars test sites

1.10   The 8 Pillars test site involves five areas: Greater Glasgow and Clyde, Highland, Midlothian, Moray and North Lanarkshire. These five areas work in close cooperation with the National Dementia Care Improvement Programme to support service improvement.

1.11   The five test sites have received improvement support through a number of learning sessions, webex calls, peer support and improvement expertise that have aimed to support test site capacity building, share learning and good practice. Each test site had a named contact and support person from the Joint Improvement Team (JiT)[2]. These three people have been closely involved in assisting each area in whatever way they required throughout the course of the test site period. One of the outputs from this support was the development of a Measurement Framework for testing the 8 Pillar model. Based on the Measurement Framework the Scottish Government gathered data from each test site which was analysed centrally. This report provides the headline results from this data gathering in chapter three.

1.12   The test sites began operation in late 2013 and the original two-year duration was extended to June 2016. Each test site received £50K per annum towards the costs of the test site.

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[1] The 8 Pillars team includes all those providing care and support for the person with dementia.
[2] Douglas Philips: Highland and Moray; Eileen Moir: Glasgow and N. Lanarkshire; David Piggot: Midlothian.

The evaluation

1.13 The aim of the evaluation, which began in September 2015, is to assess the effectiveness of the five test sites by comparing the approaches and outcomes in each area to draw learning from them on how more integrated care can deliver better outcomes for people with dementia and their carers within the current resource constraints. This has been done by:

- an assessment on the overall effectiveness of the 8 Pillars model in enabling people with dementia to stay living well and as independently as possible at home for as long as possible;

- the importance of the role of the Dementia Practice Coordinator (DPC) in that process; and,

- an evaluation of the applicability and relevance of the proposed service model in the context of wider policy landscape in Scotland, for example in the areas of the integration of health and social care, the reduction in unplanned hospital care and delayed discharge, carers' policy and the roll out of self-directed support.

1.14 At the final learning event for the 8 Pillars test sites in August 2016, Henry Simmons, Chief Executive, Alzheimer Scotland, spoke about the test sites having tested "the system's readiness" to deal with the 8 Pillars model and the challenges the system has had to contend with to adapt to it. Our sense is that this evaluation report highlights some of the areas where the system is still in the process of adapting.

2.   Overview of the five test sites

Introduction

2.1   The five areas involved as test sites are very varied both geographically and in terms of the structures and approaches they have in place. This chapter sets out a short background to each area and the approach they have taken to the test site period.We highlight key developments and activities and some of the self-reported learning.

Glasgow

2.2   In Glasgow the area selected to take part in the test site was in the south part of the city, Greater Pollok. Glasgow wanted to build on their learning and experience from the 5 Pillars pilot, which supported over 300 people with dementia, and use the 8 Pillars model to focus on supporting people with more advanced stages of dementia.

2.3   Glasgow Housing Association (GHA) planned to develop a dementia friendly area within the housing development planned for Pollok and so the original intention was for the test site to develop a model of integrated hub support across housing, social work, the voluntary sector and health. The plan also included involvement of community- based volunteer services in organising social activities and providing befriending services.

2.4   The housing development hit delays and so the planned approach did not progress and the test site became a team of Dementia Practice Co-ordinators (DPCs), hosted by the NHS, with CPNs, an OT and two colleagues from social work eachlocated within their host organisations. A Project Co-ordinator, supported by an implementation group, which considered operational matters, and a Steering Group with a strategic focus, oversaw the work of the team. Senior managers from NHSGGC chaired both groups and each included representatives from the third sector, local authority and the health board.

2.5   There were 11 people with dementia involved in the test site, nearly all identified by the CPNs based on inclusion criteria agreed by the test site. This has enabled the DPCs to fulfil a co-ordinating role for people with dementia and their families/carers and continue their involvement with clients in their care for a longer period. There has been a challenge in identifying social work cases because of the level of need required, generally at a point of crisis, to trigger social work involvement.

2.6   Glasgow faced some difficulties over the early period of the test site with some reluctance amongst staff and tensions between health and social work. However over the latter period of the test site some advances were made in relation to these problems and at the final learning event for the test sites one of the Glasgow representatives cited the positive impact on integration and multi-disciplinary working, that has resulted from the test site, as one if its unintended consequences.

2.7   While the impact in Glasgow for people with dementia was necessarily quite limited given the low numbers involved there has been greater impact for staff, both the DPCs and other staff. For example, there were opportunities for learning around personal outcomes and risk enablement plus training on managing difficult conversations which have all been cited as beneficial.

2.8   Glasgow is now in the process of developing training for unpaid carers to help them cope throughout the illness. This development has been initiated by carers themselves.

Highland

2.9   In Highland the test site area was focused on East Sutherland including the towns of Dornoch, Helmsdale and Golspie. This is a rural area serving many smaller hamlets. When the test site started, there were 125 people known to have dementia in the area.

2.10   The Community Mental Health Service within the health board has managed the test site. Health and social care integration is well advanced in Highland and is ahead of many other areas in the country as it is in the third year of a five- year integration plan. The application to become a test site was part of an overall NHS Highland plan of re-design with the reduction from 68 to 48 dementia hospital beds and an increase in community services.

2.11   Highland uses 16 Link Workers to deliver its post-diagnostic support. These Link Workers have recently had the funding for their posts extended by another two years through integrated funding.Highland is meeting the post-diagnostic HEAT target.

2.12   The Highland test site had one part-time Dementia Practice Co-ordinator (DPC) who was an OT in her professional background. She worked closely in a small team with the Link Worker for the area and the CPN (who covers the whole of Sutherland, both east and west). This small team approach worked well for them. The DPC was "hands-on" in her approach, visiting the test site patients and providing them with direct support in addition to co-ordinating others to support them. The DPC moved job to another area in Scotland in October 2015 and has not been replaced despite efforts to find another DPC. Having failed to persuade a ward manager to take on the role of DPC they are now considering having the function of DPC undertaken across the integrated care team but there are doubts expressed as to how effective this will be.

2.13   Highland has had two conferences on housing and adaptations during the test site period. These have been well attended. The discussions included incorporating a dementia-related focus into new build housing.

2.14   There is a strong sense in East Sutherland that the test site has stimulated the whole area of community connections and in particular helped encourage the Dementia Friendly Community to develop further. The test site is seen to have given credibility to what they were trying to achieve in East Sutherland.

2.15   During the test site period the Link Worker and the DPC went together to visit all the GP practices in the area. This encouraged GPs to have confidence to refer people with dementia to the DPC as they knew support was in place. However when the DPC left the area and was not replaced it left a gap in provision that has been difficult to replace.

Midlothian

2.16   Midlothian's test site takes a local authority wide approach to supporting those with advanced cases of dementia and their carers. Dementia is a key priority within the local authority and following the successful pilot of the 5 Pillars demonstrator sites, Midlothian was keen to introduce a single dementia team. The approach was modelled on the successful co-located MERRIT (Midlothian Enhanced Rapid Response Intervention Team) service, which provides a multi-disciplinary co-ordinated response to older people to enable them to stay at home and reduce unnecessary hospital admissions.

2.17   In Midlothian, the single dementia team is the DPC. It is located in Bonnyrigg Heath Centre and consists of four CPNs, three social workers, one OT, a support worker and two post-diagnostic support workers. There is a single telephone number into the team which all staff take turns to answer and this is widely advertised to services and potential clients.

2.18   At the start a different approach was taken to the involvement of social care and health care staff with social work colleagues applying for the posts and health colleagues being moved over to the team. Although a lot of work was undertaken with team members about shared roles and responsibilities and the practicalities of working as an integrated team, some matters around establishing an integrated team had union involvement and this had an impact on timescales to allow resolutions to be agreed In addition the team has faced a lot of staff turnover during the period and this hampered progress. However with the appointment of a new project lead and team leader in late 2015 the team has strengthened and is now making positive progress.

2.19   Referrals into the single dementia team come from GPs, doctors, consultants, social workers, nurses and the criteria are any of the triggers around the 8 Pillars.

2.20   The team has a weekly allocation meeting with the two Old Age Psychiatry Consultants (who undertake all diagnoses) and discuss all referrals and cases to make decisions about the health and social care of individualsand where appropriate assign the cases to the most relevant staff member.

2.21   Across the team they hold a caseload of over 200 patients, approximately 30 were originally identified for the test site. This was done simply by selecting five clients each which appeared to fit the criteria. This number has been revised down to 16, following a review of the selection procedure and deep dive into each case by the Dementia Project Officer. There is now a more detailed account of the circumstances and experience of this smaller patient cohort.

2.22 They also have multi-disciplinary team meetings every four weeks that involve all staff of the DPC, the local area dementia co-ordinator, Alzheimer Scotland Service Manager, Dementia Advisor, Volunteer Centre Service Manager for Older People, Duty and Team Leader of Social Work, Clinical Development Manager and two Consultants. These are seen to be very effective meetings for identifying opportunities for sharing information and strengthening partnershipsand the support being provided. This group continues to meet and all participants find it invaluable.

2.23 A steering group met every six weeks to provide strategic and operational support to the test site. Due to staff turnover and difficult team dynamics the operation of the test site during the first two years was challenging but the sense is that in the last six months real progress has been made.

Moray

2.24 Moray's test site covered the whole county, which is largely rural, with services mostly delivered from the towns of Elgin, Keith, Buckie, Forres and Lossiemouth. Alzheimer Scotland estimates that there are about 1750 people with dementia in Moray but that, at the outset of the test site, only around 40% had a diagnosis (though Moray compares favourably on diagnosis rates to other areas of Scotland).

2.25 Moray has a single Alzheimer Scotland Link Worker who provides Post-Diagnostic Support to around 50 people with dementia; CPNs provide Post-Diagnostic Support to a further 110 people with more complex diagnoses, medication or other clinical management needs.

2.26 The 8 Pillars test site is managed within the Moray Health and Social Care Partnership. Integration and dementia services have both been priority areas for development in Moray for many years – the Partnership published its first Joint Dementia Strategy in 2013. They aimed to build on both aspects with their application to become a test site.

2.27 Initial impetus came from the GP Clinical Lead who was keen to explore the potential for increased involvement of GPs in diagnosis and management of dementia, the relationship between Primary and Secondary Care, and with wider community care services. However it was not possible to follow through on this as the GP Clinical Lead had to return to his own practice full-time.

2.28 Moray was alsoparticularly interested to test which professions might be best placed to deliver the Dementia Practice Co-ordinator role. They identified CPNs (2), Social Workers (2), a District Nurse, a Day Services Co-ordinator, and a Community Hospital Senior Charge Nurse as DPCs each working within their own host organisation. They also considered Occupational Therapists, Care Home Managers and Family Carers for the role but, for differing reasons, did not proceed with these functions in the test. (The decision not to proceed with OTs was due to the serious shortage of OTs in the area.)

2.29   Moray established a Steering Group, chaired by the Head of Joint Operations who has responsibility for the Health and Social Care teams, and with representation from the service managers of each of the DPCs and from partner agencies including Hanover Housing, Alzheimer Scotland, and Quarriers. The Project Manager was the Partnership's Strategy Development Officer, located within the NHS.

2.30   Each of the DPCs identified two to four clients from their existing caseload to participate in the 8 Pillars test site. These clients had moderate to severe dementia and, in most cases, were receiving both health and social care services.

2.31   The test site launched with a major conference for 200 service providers from across Moray to map the range of services and activities available locally under each of the 8 Pillars. In addition, the DPCs met together early on to identify and clarify referral pathways. This process was seen as hugely beneficial in improving shared understanding of referrals and communication between the different agencies.

North Lanarkshire

2.32   In North Lanarkshire the test site area wassituated in one locality, Coatbridge. There were seven DPCs coming from a range of professional backgrounds including a District Nurse, a CPN (early onset), and the managers/staff in integrated day care centres each located within their own place of work.

2.33   Social work services within North Lanarkshire Council has managed the test site. North Lanarkshire has a strong history of integrated work stretching back around ten years and so the staff involved in the test site area are accustomed to working closely together.

2.34   There was a steering group which met on a quarterly basis plus a small operational group which met on a monthly basis with the seven DPCs. They had organised sessions on each of the other seven Pillars. They also undertook some work, facilitated by Emma Miller of the JiT, on developing outcomes for people with dementia (an outcomes-focus is generally considered by those interviewed to be one that those in social work are more accustomed to than those in health).

2.35   North Lanarkshire involves its CPNs in the delivery of post-diagnostic support and they have a waiting list of people to see. This impacts on what else CPNs are able to take on and has meant that in this test site none of the older adult CPNs has been involved.

2.36   The test site has experienced a number of key staff from the steering group leaving including the senior social work manager who chaired the steering group, the first NHS representative and the first programme manager.The Consultant Psychiatrist who was supposed to be involved with the test site went on maternity leave and there was no capacity to replace her. As in other areas staff changes have impacted on this test site.

2.37 The next chapter provides a summary of the data gathered by The Scottish Government about the test site activities and the perceptions of DPCs, carers and other local stakeholders on the role of the DPCs and the other seven Pillars.

3.   The 8 Pillars: perceptions and experience

3.1   This chapter sets out the views, perceptions and experience of the DPCs themselves, carers and local stakeholders about the 8 Pillars based on the experience they have had during the test site. It starts with a summary of the data gathered by The Scottish Government and includes examples of case studies drawn from the different areas.

Summary of data gathered

3.2   The Scottish Government gathered and recorded data from the five test sites from January 2015 until May 2016 (for Midlothian, Moray and South Glasgow) and until March 2016 for North Lanarkshire and October 2015 for Highland.

3.3   There are 99 people with dementia recorded on the data sets from across the five test site areas. The numbers break down as follows:

Highland	26
North Lanarkshire	25
Moray	21
Midlothian	16
S. Glasgow	11
Total	**99**

Gender and age balance

3.4   The gender ratio is fairly evenly split with overall figures of 55% female and 45% male. The individual test area returns show a similarly even split, with either female or male being slightly higher with the exception of Moray where the percentage of women was significantly higher (76%) and male lower (24%).

3.5   In terms of age group the biggest group fall into the 76–85 range (42%) followed by the over 85 age group (31%). 18% fell into the 65–75 age range and 8% were under 65 years old.
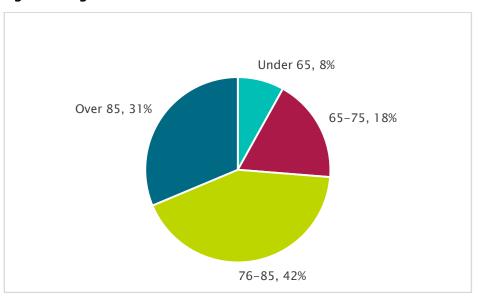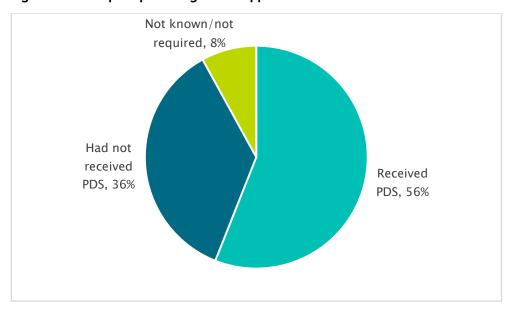
Figure 3.1: Age balance

Stage of illness

3.6   Most of those for whom data has been recorded were classed as having a moderate stage of the illness (75%). 19% were classed as severe; 2% as mild and 4% were not known. This is in line with what one might expect the main target group for 8 Pillars support to be, mostly those with the moderate stage of the illness.

Receipt of post-diagnostic support

3.7   The data recorded whether participants in the test site had received post- diagnostic support (PDS). More than half (56%) had received PDS while over a third (36%) had not. The remainder were recorded as "not known" or "not required".

Figure 3.2: Receipt of post-diagnostic support

3.8   It is interesting to reflect on the possible reasons why over a third had not received post-diagnostic support. This could be for a number of reasons: that the participant was chosen from a case- load that stretched back before post- diagnostic support was in place; that when diagnosed the participant was already well advanced in the illness and it was felt less appropriate to offer PDS.

Outcome plans

3.9   75% of the data returns indicate that the person with dementia has a personalised outcome plan, with 12% recorded as "other", 7% recorded as "no" and 4% "not known".

3.10   The data shows that 30% of carers had a personalised outcomes plan, but it is not clear how many of those involved in the overall data set had a carer, so this is likely to be 30% of a figure lower than 99.

Accommodation

3.11   The main accommodation for those involved in the test site was owner-occupied at 45%. 36% of individuals in the data collection lived alone at some point (which suggests that around this number may not have had an unpaid carer). 38% of people changed accommodation type during the course of the data collection although we do not know from the data precisely what each change involved.

Activity across the seven Pillars (excluding the role of DPC)

3.12   The amalgamated figures from the five test sites show that the highest levels of activity were in the active Support for Carers and the Personalised Support for people with dementia. The next grouping were General Health Care and Mental Health Care. There was least activity for the final three Pillars: Community Connections, Environment and Therapeutic Interventions. Activity across all the Pillars showed a decrease towards the end of the overall period. This may be because patient numbers have declined (through death or moving to a care home) or may be because they are managing better on their own or because the work of DPCs lessened as the test sites came to an end. The data does not give us this detail.

3.13   The table below shows the percentage usage of each pillar across all the sites at three different time points in the period (note: Highland did not submit data for the final two time periods shown here)
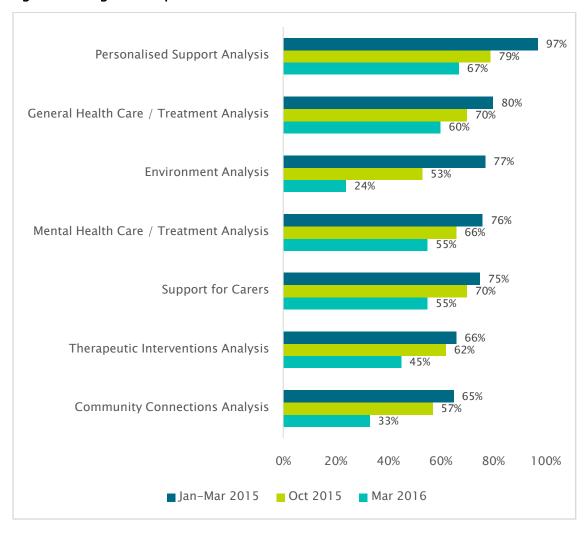
Figure 3.3: Usage of each pillar

3.14   This shows that both at the start period and at the end the highest recorded use of pillars was for the personalised support and general healthcare pillars. The lowest two pillars at the start were community connections and therapeutic interventions while at the end period this was the environment and community connections. The figures show a decrease in activity across the whole period which may be due to lower numbers of people being dealt with as they had moved into longterm care or died or that activity had decreased for example due to the lack of a DOC in Highland after October 2015.

Commentary

3.15   The data is based on a relatively small sample in each area and the time periods for each area are not completely identical. This makes it difficult to draw out much meaningful interpretation that could be said to apply more generally.

3.16   It is not clear whether data has been recorded consistently across all five areas although we understand that during the test site period attempts were made to address this issue.

3.17   There are some gaps in the information such as whether the person with dementia had a carer and whether they were in receipt of self-directed support. The steps through accommodation would also have been useful, to plot how many people from the start were able to get home after a hospital stay for example. It would have been useful to involve the evaluation team from the start in thinking through what information would be most useful to be gathered.

3.18   The next paragraphs summarise the perceptions of the DPCs, local stakeholders and carers on the eight pillars.

The role of the DPC

3.19   There has been a varied number of DPCs across the sites and they have come from different professional backgrounds. From the rural area of East Sutherland with one part-time DPC to the nine DPCs in Glasgow and the elevenin Midlothian, where the whole dementia team, including the two post-diagnosis support workers, has operated as "the DPC" together, the table below shows the different professional backgrounds of the DPCs involved.

Table 3.1 Professional backgrounds of the test site DPCs

	CPNs	OT	Social Worker	Social work carer development worker/support worker	District Nurse	Day care Service Manager/ Co-ordinator	Hospital senior charge nurse	Totals
Glasgow	6	1	1	1				9
Highland		1						1
Midlothian	4	1	3	1				9 (plus the two PDS workers)
Moray	2		2		1	1	1	7
North Lanarkshire	1 (early onset team)	1	2		1	2		7
Total	13	4	8	2	2	3	1	**33**

3.20 Table 3.1 shows that the most number of professionals involved as DPCs were CPNs followed by social workers. They all took on the role of DPC in addition to their main job role.

3.21 One of the most commonly reported views from DPCs across the test sites was that the work of co-ordination undertaken by the DPC role was "what we do anyway". The responsibility to co-ordinate care is one that sits with many of the job roles that DPCs hold. For example, OTs, social workers and managers of daycare centres all stated that co-ordination was part of their main job role. However what several DPCs added was that the 8 Pillars framework was a useful prompt to remind them to look at all aspects of the person's care and wellbeing.

3.22 A few DPCs reported that 8 Pillars' clients and their carers liked to see the 8 Pillars framework too as it made them feel more confident and less anxious, seeing a structure in place and feeling that professional staff were listening to them responsively.

3.23 One DPCemphasised the usefulness of the 8 Pillars in *"making conscious what may be unconscious"*. She found the Pillars particularly useful in their application to care homes, especially with regard to the environment Pillar. She commented that she now spends much more time looking at the environment of the care homes she visits, checking for signs that residents have their own belongings, photographs, and evidence of family contact., "*whereas previously I might have taken standards and facilities for granted*". She feels this awareness has improved practice and recording and has cascaded through the team to give even wider benefit.

3.24 For many of the DPCs the difference the test site made in their role was that they were able to allocate more time to the people with dementia who were part of the test site and very often this meant they could also give more time to the carers of those people. Carers have appreciated this additional input and welcomed the support provided. Several carers spoke very highly of the support from their DPC and some of those who live far away from the relative with dementia were re-assured to have a named person they could contact with any concerns. Carers generally value having a single named contact and several carers thought that ideally this would be someone right from the start of the journey through to the end.

3.25 There were several comments from DPCs about the lack of "clout" and that the role of DPC was not really understood more widely. (This is perhaps not a surprising view given that this was a test site and the role of DPC was a new one.)

" *'Dementia Practice Co-ordinator' doesn't mean anything to people….it needs co-ordination but someone with some clout! …the co-ordinator helps with communication…*"

3.26 Another DPC was so unsure of the role title being understood that she didn't use it at all:

"*I didn't have the confidence to use the title 'DPC' either with families or with other services*"

3.27   Others referred to the fact that another professional, perceived to be "higher up" in the hierarchy might be able to open doors more easily:

"*GPs have more clout than us to get someone referred to the mental health team and get them seen quicker (unless it was a real crisis)*"

"*Others are not aware of the role of DPC…need more done on this. We try to explain it…*"

3.28   However one DPC said that she thought the role had given her more confidence and that she could challenge more. "*8 Pillars has been useful to me…has unstuck the way I work…a refresher..*"

3.29   The case study below, from Lanarkshire, highlights the way that the lack of authority of the DPC can have an impact on the person with dementia.

> **Case Study: lack of involvement of DPC at crucial meetings (North Lanarkshire)**
>
> There was only one reference to a patient making use of self-directed support during the interviews with DPCs in N. Lanarkshire. This was someone with early onset dementia where the DPC felt that the initial SDS package offered was not sufficient and he was hoping to help get it reviewed. He did point out that the original assessment for SDS had been undertaken by social work and that he, as DPC, had not been involved. He felt that he should have been as social work was meeting the person for the first time when they came to do the assessment, while he as the DPC knew the person much better. His sense was that the DPC role did not have enough authority to insist on being present.

3.30   Several of the DPCs along with many of the carers we interviewed commented that it is very important to have a named person for the person with dementia and their family. One DPC stated:

"*Having one person as a link is very important…and getting to know them as soon as possible on their journey too.*"

3.31   Several DPCs stressed the importance of having trained staff who meet the Promoting Excellence Framework to undertake work with people with dementia. For example, one DPC noted that patients with dementia do not always have accurate self-awareness and may credibly report that they are self-caring well when this is not the case. Staff without a full understanding and good knowledge and skill base in dementia work can overlook the needs of these patients. She underlined the importance of confident, trained professionals who do not take everything at face value in assessing and working with people with dementia. The case study below from Moray highlights the importance of having awareness of the problems and challenges people with dementia may face.

Support for carers

3.32   Carers welcomed the additional support they perceived they received as being part of the test site. DPCs commented that having an allocation of some additional time to give to the test site patients allowed them to give more time to the carers involved as the case study below highlights.

> **Case study: additional time for carers (Moray)**
>
> One DPC in Moray identified additional pockets of time to allocate to her 8 Pillars clients, all of whom were clients prior to the introduction of the 8 Pillars test programme. This extra time was often used to telephone or meet with family members who needed additional support in their caring role. For example, it became apparent that the daughter of an 8 Pillars client was feeling increasingly stressed as a carer, both by the practical and emotional demands. However, the daughter did not broach her stress levels with any staff. The DPC, noticing the effects of stress, was able to arrange a face-to-face meeting with her, using her additional DPC allocated hours, and during their conversations, the daughter felt able and willing to share her feelings and anxieties.
>
> This same DPC noticed that some of her 8 Pillars clients with dementia clearly benefitted from knowing that she was giving additional time to their carers too. There was a sense of relief, for example, in seeing that a spouse was able to talk to someone about their worries, be listened to, and for help to then be put in place – for example, through additional home care or day care hours or just through the very process of "unburdening".

3.33   One of the ways in which the DPCs became involved more closely with a patient was when the main unpaid carer was unable to fulfil their usual caring role as the case study below from Midlothian illustrates.

> **Case study: intervention when the unpaid carer has a crisis (Midlothian)**
>
> Mrs X has dementia and her husband was caring for her. He was diagnosed with a terminal illness and so their daughter took over the caring responsibilities. The DPC supported the family to help Mrs X remain in the family home. The DPC focused on:
>
> • the community connections pillar finding day service provision to give the daughter some respite and enable Mrs X to socialise with other older people in the setting;
>
> • the environment pillar of the model, organisations adaptations to the home that would help the daughter undertake aspects of care;
>
> • the general health care pillar by reporting on the changes in Mrs X's behaviour so that when changes to her medication were required these were addressed in a timely way so that she could remain safely at home.

Personalised support

3.34   For many DPCs this is an aspect of their main professional role that they would see as being central to what they do anyway. We explored whether the DPCs' own professional role had some bearing on what they did as a DPC and found that there was some relation between the two. For example, the CPNs who were DPCs were more likely to review medication and the social workers/OTs more likely to review the adaptations in the home. In Midlothian, where they work as a single team, this apparent focus on "traditional" areas of responsibility is changing with the appointment of the new team leader and project lead. However, it suggests that there is more work to be done to encourage DPCs to move out of their own professional comfort zone when working with individual patients.

3.35   In Midlothian they are piloting the use of Family Group Conferencing (FGC) to work with the families and carers of people with dementia to empower them to look at options and reach decisions about care and support so this provided an opportunity for families to be referred to the FGC process.

3.36   A case study from Moray illustrates the kind of support that the DPCs might offer.

> **Case study: personal support with financial issues (Moray)**
>
> One DPC worked with a client who had complex health problems. Her family all live in London so when the client needed additional assistance to sort out financial issues, her DPC was able to undertake the required intensive liaison with family members. The DPC was able to undertake this work directly because of her own background in community care and because of her wide remit as DPC.

The environment

3.37   There has been a lot of different activity in relation to the environment pillar including housing conferences in both Highland and Moray and new activity being stimulated in these two areas and Midlothian through greater awareness. The Hanover Housing case study in Moray, outlined in the next paragraphs, provides a good example of this new activity.

> **Case Study: Hanover Housing (Moray)**
>
> Although Hanover Housing in Moray found they could not devote specific time to representation on the 8 Pillars' Steering, nonetheless their involvement in the test has informed plans for major housing developments and service re-design which commenced prior to the 8 Pillars test. Forres will have seven designated flats for dementia care and Elgin has six designated for handover in 2016. It is likely that Hanover Housing will depart from its traditional remit by directly providing home care to ensure 24 hour staffing for their extra care housing.

> Hanover's management re-structuring will take account of these developments, recruiting a specialist care business manager with a Scotland-wide remit. A joint allocations panel will consider application forms with add-on sections relevant for dementia. There have already been 40 enquiries concerning these properties. Moray Council Social Workers, District Nurses and the relevant Hanover Housing managers will meet in case conferences to discuss allocations.

3.38 In Midlothian the Project Lead has been undertaking joint work with Midlothian Council's Commercial Services to produce guidance that can be used to develop more dementia friendly designed housing and to enable housing and maintenance staff to take measures that may support people with dementia in their homes. This includes producing guides for housing officers and training for maintenance workers.

3.39 The case study below highlights some of the common-sense environmental issues that may need to be addressed in order to avoid medical crises.

> **Case study: addressing immediate environmental (and social) issues (Glasgow)**
>
> The DPC (a social care worker) was asked to go on a duty home visit to meet with Mrs A and her daughter as a crisis had arisen due to Mrs A's husband Mr A, the main carer, being admitted to hospital for emergency surgery. This meant that Mrs A would be at home on her own without any support in place. Daughter B and her dad were requesting emergency respite admission for Mrs A given she had dementia and had never been on her own before. Daughter B worked fulltime and had a young family of her own. The DPC's objective was to meet with the family and look at putting in relevant support, firstly to reduce immediate risks to Mrs A and the caring role for B, and secondly to gather evidence of Mrs A's needs and if she could remain at home safely. The various actions she took are listed below.
>
> - Daughter B advised that her mother suffered from falls so the DPC firstly suggested she remove her mother's ill- fitting slippers and replace them with more supported footwear. The DPC also suggested removing all the small rugs from the floor to prevent her mum tripping. She suggested that the daughter consider getting a keysafe to allow access to visiting services and prevent her mum from having to walk to the door thus reducing the risk of falls.
>
> - The DPC arranged an urgent referral to the community rehab team on Mrs A's behalf to receive an updated physio and OT assessment. She also re- referred Mrs A to the CPNs to have her medication reviewed as it had been prescribed for over two years without review.
>
> - The DPC arranged for homecare four times a day, seven days a week. This was to assess Mrs A's needs to be assessed. It would also ensure she was being offered assistance with personal care, meal prep and a medication prompt daily. The DPC

arranged a daycare placement with immediate start which would allow Mrs A to be in receipt of social/intellectual stimulation and have her needs assessed by other professionals.

- B had concerns about her mother being on her own overnight so the DPC arranged for sleepover support, four nights a week for a period of two weeks to have Mrs A's night time behaviour monitored.

- The DPC arranged for a Home Fire Safety Check to reduce risk of home fire and to get an emergency plan in place.

It was determined that Mrs A was able to remain in her own home with only limited risk, with the above supports in place. Mrs A's husband was discharged from hospital and the daycare placement was reduced to three days per week and homecare to twice a day, whilst the overnight support was discontinued.

This case study illustrates the range of practical inputs required in order to ensure someone can remain at home.

Community connections

3.40   The 8 Pillars model assumes that there will be a level of community connections available to which people with dementia may be referred. In each of the test site areas there have been developments to address this, some of which were building on what already existed. The range of activities include daycare centres, dementia cafes, social groups and support such as Shared Lives and Dementia Adventures. Two areas, Highland and Moray, started the test site process by having events to bring people together to map everything that existed within the community to support people with dementia.

3.41   DPCs stressed the importance of keeping up to date with all these opportunities and activities in their area.

3.42   Carers in two areas commented on the boost the test site status had given to accessing funding to continue to develop the supports and activities in place. They also commented that access to such supports and activities is important throughout the person's journey through the illness.

3.43   The following case study from Midlothian illustrates one approach to using the community connections to improve the quality of life for a person with dementia. It could equally well be used to illustrate personalised care.

> **Case study: accessing community support (Midlothian)**
>
> Mr Y lived by himself in another local authority area and when his dementia started to progress he moved to the area to live with his brother and sister-in-law who both worked full time. Mr Y was a former landscape gardener and so the DPC worked with Mr Y to find appropriate support within the community and connected him with a gardening club so that he continue to enjoy gardening and spending time outdoors. The club supported his involvement by picking him up and dropping off at home. His brother and sister-in-law planned a six month stay in Australia. It was not possible for Mr Y to stay in the family home whilst they were overseas so the DPC arranged temporary sheltered accommodation within a care complex. She worked with the occupational therapist who undertook a Road Safety Assessment with Mr Y and they sourced a GPS system so that he could be located when he went wandering. The community within the care setting were very aware of the needs of Mr Y and they allowed him access to the local greenhouse and to work with the gardeners so that he could continue to enjoy his gardening.

Therapeutic interventions

3.44   This was the least understood of the pillars mainly because the definition was not clear/accepted fully by all. The Alzheimer Scotland model sets out the definition for this pillar as being about *"dementia-specific therapies to delay deterioration, enhance coping, maximise independence and improve quality of life".*

3.45   For some with a psychological background this pillar was about cognitive behaviour therapy and cognitive stimulation therapy whilst others took a broader view of this pillar, including any activity that might be of therapeutic value to the person even if it wasn't "dementia-specific", for example, joining a walking group.

3.46   There was also some overlap between what belonged to "community connections" and what to "therapeutic interventions": for example, a football reminiscence group might be classified in either. As a result this pillar had the least recorded activity against it in the data gathered.

General medical and mental health care and treatment

3.47   Not surprisingly, DPCs understand these two pillars well and reported noting changes in behaviour that might suggest a possible need for changed medication or a review of healthcare treatment. The DPCs who were health professionals might provide these services directly themselves while non-health specialist DPCs referred clients to GPs, District Nurses and CPNs or to the dementia team as appropriate.

3.48   The link between medical healthcare needs and social wellbeing needs are closely inter-related and this is one of the strengths of the 8 Pillars model. Two case study examples

from Highland and Moray illustrate the close links between medical healthcare needs and social wellbeing needs.

Case study: attending to social wellbeing impacts on healthcare needs (Highland)
In Highland the DPC intervened to support one patient, who had been being admitted to hospital frequently due to falls. She identified one of the issues for this person as isolation and provided hands-on support accompanying him to the local Hub several times until he was confident enough to go himself. At the time of this evaluation there had been no falls since she put this support in place and no further hospital admissions. This is an excellent illustration of the upfront, reasonably time intensive, prevention approach which saves resources in the longer term.

3.49   The next chapter sets out overall findings from the test sites.

4.   Overall findings

Introduction

4.1   We set out the findings from the evaluation under the following headings:

- Context;
- Application process and structures;
- The operation of the test sites;
- Facilitators and barriers;
- Impact;
- Unintended consequences; and,
- Learning.

Context

4.2   The timing of these test sites, coinciding with the integration of health and social care, has meant that there have been significant and important changes taking place at the same time as the test site process and,not surprisingly,the attention of senior management has been focused on the integration process. It is hard to quantify what impact this has had on the test sites but there is a strong sense from those interviewed that this backdrop has not helped with holding the focus on the test site actions.

4.3   The 8 Pillars model sits within an overall model, as described in chapter one, drawn up by Alzheimer Scotland, of which the post-diagnostic support, the 5 Pillars, is the first stage. There was a national HEAT target for the health boards to meet this 5 Pillar support and this was inevitably given high priority. In some areas this was not an issue. For example, in Highland (where they make use of 16 Link Workers to provide the 5 Pillar support) there is no waiting list for the post-diagnostic support and the HEAT target is met whereas in North Lanarkshire the CPNs are involved in providing post-diagnostic support and they were finding it difficult, due to capacity issues, to meet the HEAT target. This meant that it was impossible for the CPNs from the older services team to be involved in the 8 Pillar work.

4.4   The overall model of the 5 Pillars support, a period of self-management, the 8 Pillars support and eventually advanced stage support is an ideal scenario which inevitably is not always the reality. The illness can advance much more quickly or slowly than expected. In two rural areas, Highland and Moray, it was reported that some people do not like to get an early diagnosis and so they delay going to the doctor: their sense is that many of the newly diagnosed are immediately ready for 8 Pillars integrated support following on from or concurrent with the 5 Pillars support. It is clear from the data gathered about the patients involved in these test sites that several have died during the course of the test site which

might suggest either that their illness advanced more rapidly than expected or that they were already more advanced when they began to receive the 8 Pillar support. One carer we interviewed thought that the test site 8 Pillar support has been closer to the advanced end of the illness and that it should be available sooner, throughout the self-management period. Others thought that having one set of pillars might be helpful.

4.5 One of the issues raised during the evaluation, particularly by carers, which relates to the previous paragraph is that after the 5 Pillar support when the person with dementia is in the self-management period, the case is closed until such time as it becomes apparent they may need further support. While this may be a process that works for some patients and their carers, the reality appears to be less straightforward: that someone may be managing well during self-management but then a crisis occurs (for example, their unpaid carer becomes incapacitated) and they need to find support quickly. In Highland it was reported that people tend to revert back to their Link Worker as they have established a relationship with this person and that the Link Worker will try to do what they can even although the person is no longer technically on their caseload. The need for continuity and relationship building with a named person is something that many carers and some staff have raised.

4.6 The ongoing pressure on resources nationally has had an impact on the test sites in different ways. For example, in Moray they did not appoint an OT as a DPC as there is a scarcity of OTs. In Glasgow, social work has priority criteria to determine which people they can work with, in order to focus resources where they are most needed, which meant that only people with advanced dementia who are in crisis could be allocated to DPCs. (This was given as part of the reason why numbers in Glasgow have been lower than elsewhere).

4.7 The local context has affected the way in which the test sites have operated both negatively and positively. In Glasgow there was disquiet amongst the CPNs about their involvement in the test site following their piloting of the 5 pillars model. In addition, the acknowledged tensions between health and social work, have affected the way in which the test site has operated and, although more recently there have been some improvements, it meant that in the early days they made less progress (another part of the reason for the low number of people with dementia included in the test site). In contrast, Highland, Moray and North Lanarkshire reported that they had been well advanced with health and social care integration (prior to the formal integration announcement) and for these areas this has not been an issue.

4.8 On the positive side, Midlothian had an established and a successful integrated team approach on which to model a single dementia co-located team and which created the vision of how the single team could operate. Although the team has faced several challenges, relating to strained team dynamics and instabilities, the co-location of a dedicated dementia team, including the post-diagnostic support workers and weekly input from the Consultants for Old Age Psychiatry ensures a holistic approach to patients with dementia across Midlothian.

Application process and structures

4.9   The way in which the application process happened in each area has some bearing on how easily the test site worked. In Glasgow the application was made by senior management centrally without consultation with those who were going to be responsible at local operational level where it appears there was less appetite for it. In North Lanarkshire the application was led by social work and there was less buy-in for it initially from the health partners at senior level.

4.10   In terms of structures the test site has been managed by the health board in two areas (Glasgow and Highland); by the Head of Joint Operations in Moray; in North Lanarkshire the programme management sits in social work; and in Midlothian it lies within Older People's Services within the Council. However where it is managed by the health board it also lies within different service areas: in Highland it lies within Community Mental Health Services, in Glasgow it sits within the Glasgow City CHP, now Glasgow City HSCP.

4.11   Each test site has had a steering group in place to oversee the process with representatives from health and social care plus Alzheimer Scotland. These met regularly in the first two years of the test site butless frequently in recent months when there has been a sense of the test sites trailing off, even although the time period was extended to June 2016 (the exception being Midlothian where planning for the future and further analytical work on the test site is being undertaken).

4.12   The 8 Pillars approach assumes that the other seven Pillars and, in particular, the "community" ones are in place: what one interviewee referred to as the "eco-system of dementia care". In all test site areas, there have been significant developments of dementia friendly communities and a number of structures are in placewhich mean that it is easier to provide the community support to people who need it at the 8 Pillars stage. The diagram overleaf is an example of the way in which one area (Highland) has thought through what might be needed in relation to each of the 8 Pillars: Midlothian has developed something similar. North Lanarkshire has also developed a number of supports in relation to dementia friendly communities. In Moray at the start of the test site process they held a conference to map out services and community connections across the seven Pillars, attended by 200 people. Those interviewed regarded this as an excellent way to gather and share information and build relationships. As in Highland and North Lanarkshire, Moray already had a range of dementia-specific services in place including dementia cafes and Dementia Adventures.

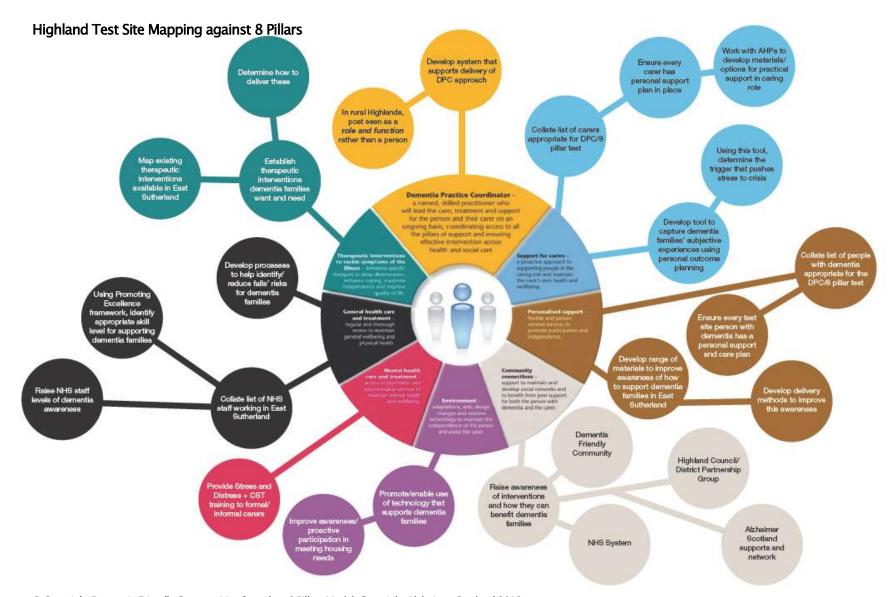## The operation of the test sites

The DPCs

4.13   In terms of the co-ordinating function of the DPC role and which professions the role is suited to, the main example where this has worked less well is the District Nurse in North

Lanarkshire where combining the co-ordination function with the much more task-oriented functions of a District Nurse proved more difficult. The District Nurse in Moray on the other hand found the DPC role was not dissimilar to her pre-existing role. The Hospital Senior Charge Nurse in Moray, however, found the DPC role impossible to combine with his existing hospital-based responsibilities. For other professions, such as CPNs, OTs, social workers and day care managers there was a strong sense from interviewees that this co-ordinating function is what they already do and that while the 8 Pillars is a useful framework they would anyway have been co-ordinating support and care as part of their job.

4.14   In one area, Moray, they considered whether unpaid carers who had already undertaken relevant SVQs in Care could take on the role of DPC. This idea was not progressed but some of those we interviewed thought that this should have been tested. The arguments against it were that it would be difficult for carers to co-ordinate care provision with health and social care staff at more senior levels; to meet the Promoting Excellence Framework requirement; and that they might feel under pressure to assume the role.

4.15   In Midlothian the whole of the dementia team was considered to be the DPC. The key issues here have been the group dynamics, instability of the operational management of the team with turnover of staff in the team leader role and therefore an absence of strong management to address team dynamics and tackle some of the difficulties. These difficulties are now being addressed with the appointment of a new project lead and team leader.

4.16   The approach to the role of DPC varied: in some areas it was "business as usual" with support co-ordinated as and when needed, often at the point of crisis. In other areas there was a more proactive, hands-on approach where needs were identified and action taken to address them. The problem with the latter approach, which worked very well for people with dementia, was that it was time-consuming, at least for short amounts of time (but with potentially cost-saving benefits and a reduction of resource needed in the longer term.)

4.17   In general the DPC role in the test sites has had a stronger emphasis on crisis interventions than on prevention as seen in some of the case study examples included in the previous chapter. This is not how the 8 Pillars model was originally intended, where the focus was supposed to be on improving quality of life and helping prevent crises and unnecessary hospital admissions.

Highland Test Site Mapping against 8 Pillars

Selection of test-site patients

4.18   The test sites took a pragmatic approach to the selection of patients to participate in the testing process. In Moray the criteria used were that they should be existing clients with more advanced dementia than those in receipt of Post Diagnosis Support so most of the 21 people selected were already receiving support from both health and social work services. In Highland the idea was that the DPC would pick up from the Link Worker once the personal support plan was in place, but in practice they found that some patients were being diagnosed with advanced dementia and immediately became part of the 8 Pillars integrated support. In Midlothian, where they have a specialist dementia team approach, there was the opportunity to discuss across all their patients which ones would benefit most from the 8 Pillars support. In North Lanarkshire they began by looking at the current caseload of people who might need more help; they then looked at the "next two people who come on your caseload" but found that some of these were already too advanced in the illness; so they reverted to identifying people who might benefit from more support from the existing caseload. In Glasgow they struggled to reach even the target number of 20 and only managed to work with 11 people with dementia due to a number of reasons. This was partly because the criteria social work applies means that only those who reach a crisis point could be included; partly due to the small geographical area that the test site covered; and partly because carers/family members of potential participants were asked to sign consent forms for data sharing purposes and this deterred some from agreeing.

4.19   Overall, the perception of those interviewed is that patients do not neatly fit into the overall model of 5 Pillars, a period of self-management, followed by 8 Pillars integrated support, followed finally by an advanced stage support period. It should be noted that Alzheimer Scotland did not envisage that the model would be as rigidly demarcated in this way as possibly some have perceived it to be. In the test-site areas many of those selected were already at an advanced stage of the illness. One carer spoke with great conviction about the need to make 8 Pillars support available throughout the "self-management" period as crises occur where support is required even if, in general terms, the person is able to self-manage. She suggested that people with dementia should not have their cases closed at the end of the 12 month post-diagnostic support period but instead these should remain as "open" cases so that they can call on help as and when needed. The 8 Pillars integrated support shouldbe available to those who need it immediately after the post-diagnostic period finishes. (For some people access to the 8 Pillar support may even need to be available during the post-diagnostic support period if they have not had an early diagnosis).

4.20   For those managing cases however, particularly within health, it is difficult to keep all cases as "open" as they need to prioritise those with immediate healthcare needs. Ways to ensure support is provided in a timely way need to be explored: one suggestion from this evaluation is that at a minimum the post-diagnostic support worker introduces the

person with dementia and their carer/s to the named person who will act as their DPC, thus providing a seamless continuation of care. At present, because there is not a seamless continuation, the sense of demarcated areas between the different pillars and being able to access support, is the experienced reality.

Self-directed support

4.21   There have been relatively few mentions of self-directed support being used by those people with dementia involved in the test site.   Information about self-directed support was not routinely gathered as part of the data collection exercise so the information available has come through anecdotes during interviews and qualitative information recorded as comments in the data gathering. Where it has been mentioned it appears that it has been used to help increase access to paid care and support for unpaid carers. For example in one instance the wife of someone with dementia is recorded as being able to have an overnight respite break as the SDS package has allowed for paid care overnight to allow this to happen.

Communication and referral

4.22   Communication and referral are core to the effective co-ordination of support for people with dementia and their carers. This is partly about the communication between the DPC and the person with dementia and their carer in order to establish a good relationship and understanding between them. It is also about the communication between professionals within the public and third sectors who are there to support people with dementia. There have clearly been tensions between health and social care staff in two of the test site areas we reviewed which have already been alluded to: these tensions do not assist the effective support for people with dementia and their carers.

4.23   In addition, it is important that communication between health /social care workers and those within the community who can provide support are well established and that what support can suitably be offered is well understood. For example, in one area people with dementia who have a range of other health and care issues such as incontinence were being referred to a volunteer-based organisation where they were not equipped to deal with these issues. Appropriate referral and understanding clearly what can be suitably provided is essential.

4.24   Information-sharing is part of good communication. There are still issues around health and social work sharing information in real time and of different systems being used. For example in North Lanarkshire the community teams use Midas,the acute services use Track Care, the GPs use GPAS and SkyGateway and social work uses SWIS. It was reported that there is still duplication in terms of inputting information. DPCs and partner service providers in Moray also highlighted the lack of shared assessments. While it is understood that some assessment information must be confidential and restricted, there are long-standing IT and professional barriers to sharing information. So, for example,

although Social Workers provide some of the care, they cannot read District Nurses'
anticipatory care plans. In addition, there was a feeling that plans needed to be
streamlined a bit: at the moment, there are personal plans, person-centred patient
plans, as well as anticipatory care plans and nursing assessments.

Involvement of GPs

4.25   The involvement of GPs in the test site areas has been variable. In one area (North
Lanarkshire) despite direct attempts to involve GPs the response has been very limited. In
Moray a local GP was very involved at the outset but had to withdraw due to practical
constraints within his own GP practice. Much of the diagnosis of dementia in Moray is
made by two Old Age Psychiatric Consultants, with follow-up from CPNs in the Mental
Health team. There was a recognised need to increase capacity to make early diagnosis
so, in addition to the Consultants providing intensive support to GP practices, six GP
Scholarships on a dementia diagnosis programme offered by NHS Grampian in Aberdeen
were purchased using 8 Pillars test site funding. However, participating GPs found the
distance to Aberdeen meant too much time away from their Practice. There was a general
recognition amongst interviewees that diagnosis rates are improving in Moray but GPs
interviewed confirmed that there remain issues of confidence and training – dementia
diagnosis is not straightforward – as well as contractual issues, with several GPs citing
financial disincentives.

4.26   In Midlothian, the GPs make a referral to the two Old Age Psychiatric Consultants who
make all the diagnoses.

4.27   In Glasgow the DPC co-ordinator visited the nine GP practices to inform them of the test
site. The GPs provide the nationwide 15 month review of patients with dementia and
those GP practices with patients on the test site have the consent to share form and so
there is a regular exchange of information between the DPC and the GP, for example,
about out of hours contacts.

4.28   In Highland the DPC and Link Worker made a specific effort to visit each GP practice in the
area to tell them about the support available. This led to a perception among those we
interviewed that more GPs were making diagnoses as they knew the support was in place
within the community if they did so. However the reported downside has been that now
the DPC is no longer in place there is no-one to provide the co-ordination of community
support and they are now having to tell GPs that this can no longer be provided.

Leadership

4.29   The leadership of the test sites has been important and where it has worked well it has
largely been due to the personal commitment of those involved. Some of the senior
managers involved are highly committed to the need to provide effective support for
those with dementia and work hard to ensure partner relationships operate well. In some
instances the fact that key senior staff have left during the testing period or the fact that

relationships between partners are already poor have impacted on what the test site has been able to achieve. In Moray, the early withdrawal of the GP Clinical Lead from the Steering Group meant connections with GPs were weaker than anticipated at the outset. Some services not directly involved in the 8 Pillars Steering Group felt that there was insufficient sustained direction given to DPCs to ensure a more holistic, improved provision rather than status quo.

4.30   In Midlothian the changes and the episodic absence and multiple change of team leader over a prolonged period potentially had a negative effect on the functioning of the team. The recent appointments at the end of 2015 have resulted in a noticeable change in the team dynamic and real progress over a few months with strong and focused leadership.

Support from the Joint Improvement Team

4.31   The support received from the three members of the Joint Improvement Team (JiT) was highly regarded in all of the test site areas. Each area was able to choose how to use the support available and welcomed this flexibility. Local stakeholders spoke of the difference the hands-on support had made with a wide range of operational issues.

Facilitators and barriers

Facilitators

4.32   The 8 Pillars model is seen as a useful framework and aid and supports good practice in working with people with dementia and their carers. Many of the DPCs commented that it reminded them to examine all aspects of a person's life, not just the aspect most directly concerned with their own professional practice.

4.33   There have been huge learning opportunities for the DPCs involved in the test site areas and this has often also extended to other staff in each area including awareness-raising for daycare staff and for maintenance staff.

4.34   In each area, at different points of the process, there has been excellent and committed leadership. The test sites have operated,as has been seen, at quite a challenging time in terms of the context of integration and without the level of commitment shown by key people would not have achieved as much as they have.

4.35   The co-location of post-diagnostic support workers with the DPCs in Highland and Midlothian has had benefits for people with dementia and their carers: it makes the provision of seamless support much easier to deliver and allows the workers involved to discuss the needs of the individuals they are helping so that the most appropriate support is provided. The close linking of the work of the PDS workers and the DPCs seems to be an important element going forward.

Barriers

4.36   The internal hierarchies within health acted as a barrier in some instances to DPCs having the necessary authority to open doors and co-ordinate support with ease and in a timely fashion.

4.37   Barriers arose, mentioned earlier in this chapter, because of the context of integration and the staff changes that went alongside this.

4.38   Staff and carers in rural areas raised issues that were less apparent in more urban areas. In particular the problems of transport: even where services are available in the community it may be difficult for people with dementia to get to them. In some rural areas the services available tend to focus on towns and inevitably this leaves some people more isolated. (However, a positive factor in some rural areas that was mentioned is that the sense of neighbourliness and caring for members of the community is perhaps stronger than in more urban areas.)

4.39   While there were positive examples of excellent leadership, the reverse was also found: that in a couple of areas there had been difficulties in leadership, sometimes due to turnover of staff, and that this had had a negative impact on the test sites.

4.40   There is still a lack of shared real time information and assessments between services. Some areas stated that there are moves to try and address this issue and hopefully integration will speed this process up.

4.41   Some of the Pillars, in particular therapeutic interventions, are not fully understood or there are different interpretations. From the data gathered it appears that this lack of understanding can make practitioners less likely to use this pillar.

4.42   The strong perception from some DPCs and many carers is that there is a risk of gaps in provision between the different stages of the model and for some people they would prefer one set of Pillars and a stronger sense of seamless support, as and when needed.

Impact

4.43   It is hard to draw overall conclusions about the impact on people with dementia and their carers as the numbers involved in the test sites have been so small. There is anecdotal evidence of the positive difference it has made both to patients and to their carer/s.Part of the impact appears linked to the fact that practitioners, the DPCs, could spend a bit more time with those who were selected to be on the test site.

4.44   One of the aspects that carers find helpful is having a named person to whom they can turn: for relatives who do not live near the patient it can be very reassuring that there is someone known to talk to if they have concerns.

Unintended consequences

4.45   The impact of the delivery of the 5 Pillar HEAT target on the 8 Pillars delivery was not intended, for example in North Lanarkshire where it has meant older people's CPNs are not available to provide 8 Pillar support.

4.46   There have been various opportunities to undertake training as part of the DPC role. Several members of the Glasgow team acknowledged the personal benefit of the 'Holding difficult conversations' training on their own confidence and ability to discuss sensitive and difficult matters with carers and family members but also in appreciating the difficult conversations that their social work colleagues were also having, e.g. moving someone out of the family home.

4.47   In Midlothian, the post diagnostic support workers are part of the single dementia team and they considered this a uniquely valuable position. It allows the PDSW access to the Consultants at the weekly meetings and to their DPC colleagues so that they can talk about 5 pillar cases that might need to be referred straight to 8 pillars or even refer a late diagnosis to the DPC for the post diagnostic support because of the advanced stage of the dementia.

4.48   In Highland there was a strong sense that because they had the recognition and credibility as a test site that they were able to make other connections enabling them to put in place a number of community connections elements that might otherwise have been harder to do.

Learning

4.49   In Glasgow: the team recognise that the test site area was too small but once it was apparent that the housing development was delayed, there was no opportunity to shift to a different geographical area in the south because the work and preparation with the team had begun. The test site is led by health and whilst the steering group and implementation groups had wide representation from public and third sector partners and full support from social work the senior managers acknowledge that had their social work counterparts jointly chaired the operational and strategic groups this would have secured better engagement.

4.50   In Highland: a sense that the 5 Pillars and 8 Pillars could be merged as people are coming to diagnosis so late in the day. This is viewed as a rural phenomenon with people knowing they are not well but not wanting to have the label attached in a small area where everyone knows each other.

4.51   In Moray: most people interviewed felt that the dispersed model of DPCs has advantages in a rural area at a time when resources are scarce. However, all Moray DPCs noted that they only provide this intensive support to their clients as and when it is needed and managers noted that not everyone in the 8 Pillars "stage" necessarily has on-going

contact with a District Nurse, CPN or Social Worker. They think that the model of providing this level of continuous support to everyone with dementia is unsustainable. Rather, they think that more aspects of community- and self-management should be developed for people who do not require on-going intensive clinical or social care.

4.52   DPCs in Moraysupported co-location where possible and some Managers favoured multi-disciplinary locality teams based in Primary Care – not a Social Work Team with a bolted-on CPN or vice versa but fully integrated. One very positive outcome from the test has been the model now being piloted in Ardach surgery, Buckie with the appointment of a Dementia Practice Nurse. The Ardach surgery pilot opens the prospect of a co-ordinating role based in GPs surgeries, with funding shifted from Secondary Care to Primary Care as GPs and community nurses take on more dementia diagnosis and management.

4.53   In Midlothian the model for the integrated team was tried and tested but the approach to establishing the single dementia team could have been more effective (CPNs already in post in an established team and social workers applied for positions in an integrated team). With a freshly integrated team and multiple changes in team leader and team members it was a challenge for the DPC role to be embraced an embedded in a fully functioning integrated team which prevented the integrated team from fully functioning.

4.54   In North Lanarkshire where social work services were leading the test site there was more difficulty in engaging the GPs: while it is not possible to prove a causal link between these two elements it is interesting to note it. There were attempts here to take an outcomes-based approach to the support work with people with dementia using Talking Points as the vehicle for this. One of the problems identified is that unlike outcomes work with children and young people where the GIRFEC framework is in place, there is no such framework for older people. The facilitator for this work stated that working on personal outcomes was new for the health practitioners involved while social work staff were familiar with working in this way. Another interviewee commented that the test site endorsed what was an existing model of integrated working (particularly through the integrated day care centres). The test site triggered a whole staff review of what level of dementia training people have which probably might have happened anyway but at a later date.

5.   Conclusions and suggested improvements for the future

Conclusions

5.1   The test sites were operating at a time of significant change in health and social care structures. These changes had a negative impact on the progress of the test site in some of these areas.

5.2   In all the test site areas the currentpressure on resources has been felt in some way whether in terms of changes in staffing, staff capacity to take on additional work, or criteria being set for which cases you can work with.

5.3   The test sites have demonstrated that there is some excellent work being done to support people with dementia within the community and they have encouraged a focus on ensuring that good community supports are in place.In three of the areas this has included a focus on housing and housing related adaptations for people with dementia. These developments are to be welcomed.

5.4   The 8 Pillars model is welcomed as a useful framework. Both staff and carers we interviewed view the DPC role/having someone to co-ordinate support, as an important one. In order to be effective the people undertaking this role have to havethe mandate and be trusted and valued by partners in order to be able to make things happen. Having enough authority to deliver the role and open doors was challenging for some DPCs in the test site areas: it appeared easier where the DPC was already well known and where they were co-located in a multi-disciplinary team. The views expressed indicate that the role can sit well with a number of different professionals including OTs, social workers and CPNs. Those undertaking the co-ordinating role need to have the Enhanced level or an equivalent (some DPCs had a Masters degree through Stirling University).

5.5   The test sites appear to have offered the 8 Pillar support to some patients who were at the more advanced stages of the illness. There is a strong sense from interviewees (and this is endorsed by Alzheimer Scotland) that the 8 Pillar support should be available as a preventative measure and not simply brought in at crisis points. The 8 Pillars should support better co-ordination of health and wellbeing outcomes throughout the person's journey, after the initial period of support, and not just when things become very difficult.

5.6   The overall model of 5 Pillars post-diagnostic support, a period of self-management, 8 Pillars integrated care support followed by advanced care support is a useful model for the kinds of support that may be needed but the approach needs to be focused on each individual's pathway through the illness and the provision of continuing support. Having one named person throughout this pathway, rather than a stop and start approach,is the ideal: how this is put into practice is probably going to have to vary from area to area because the structures in place are so different. One suggestion is that at the very least

the named post-diagnostic support worker should hand over the person with dementia at the end of the 5 Pillar period to the named DPC, even if the person is not immediately going to need the integrated care support that the 8 Pillars provides. This might go some way to alleviating the sense of "dropping off the radar" that at present is expressed by carers after the PDS period ends.

5.7   It is not clear how much that is very different or new in relation to co-ordination has been tested during this period: many of the DPCs commented that co-ordination is what they do anyway as part of their job. However from anecdotal evidence it appears that the test sites did encourage a greater focus on the supports available in the community and the environment and on a more holistic approach to the needs of the people involved. It also appears that there has been heightened awareness of the needs of people with dementia, not just for those involved as DPCs but also for staff working alongside them.

Suggested improvements for the future

5.8   A person-centred approach would be to have the same named person throughout the person's dementia journey from diagnosis to death. This would provide continuity for both the patient and the carer/relatives and allow the person with dementia to be known by the named person before the illness advances so that their likes and dislikes are well understood. This has come strongly from interviews across the areas: that there should be one named person from the start to accompany the person with dementia on thewhole of their journey and that in this respect it is a long- term condition. The named person should only change if the staff member moves on for any reason.

5.9   If this is not practicable then a second suggestion, as noted above, is that the PDS worker should introduce the person with dementia and their family/carer to the person who will be their named DPC so that this contact is established before any period of self-management. In this way, if there is any need for support, the person with dementia or their family/carer knows whom to turn to.

5.10   Self-management is not seen to fall easily into a neat period; people may have days when things are more difficult and they need more support and then another period where less support is required; carers may also have unexpected crises meaning that support is suddenly required for the patient. They need to be able to access support easily throughout the journey. For this reason interviewees have stressed the need to make the 8 Pillars support available before the illness is too advanced and as and when it is needed.The introduction to the named DPC would facilitate this process.

5.11   It is not realistic, and was never envisaged as such by Alzheimer Scotland, to imagine that there can be a whole new set of professionalswithin the workforce called DPCs with this as their sole remit.Each area must however decide how it is going to fulfil the function of having a named person who can provide the support required throughout the person's dementia journey. In some areas the number of Link Workers might be increased and

these people could be trained to take on some of the 8 Pillars and advanced care co-ordination. In other areas this function may sit well with a range of other professionals. Having a multi-disciplinary team with a focus on support for people with dementia, as in Midlothian and Highland, is an ideal that other areas might wish to consider adopting. The co-location of PDS and DPC staff appears to be beneficial.

5.12   It is likely that some form of further support, including resources, will be required to ensure that the 8 Pillars and advanced care co-ordination can be put in place across Scotland.

5.13   The issue of shared information systems and information sharing has to be addressed if real co-ordination is to take place effectively. In some areas this is beginning to happen with health and social work bringing some of their systems together. It is to be hoped that integration will speed this process up.

5.14   Overall the future is about gearing the system up to be ready to provide post-diagnostic, integrated and advanced health and social care and support, effectively.

APPENDIX 1 –RESEARCH TOOLS

Dementia Practice Co-ordinators (DPCs)

Introduction

Recap about the DPC model used in this locality

Your role

1. What does your role as DPC entail? (*explore in detail covering the following*)
    -co-ordination of services
    -relationships with people with dementia and their carers
    - percentage of time spent undertaking the DPC element
    -team working /professional relationships (particularly for where there are several
    DPCs explore how they work together)
    - ability to unlock/circumvent to provide solutions and support

2. Have you been trained through Promoting Excellence? What level are you at on it? What difference has being trained to this level made to your role?

3. Do you feel well supported by the rest of the "system" in delivering your role? Do you think that others understand what your role is?

8 Pillars

4. Have you been using each of the other 7 Pillars? In what way? (Explore each one to see if it has been used.) Are there some that you use more than others/don't use at all? Do you think there is anything missing from the 8 Pillars?

5. What is your view on the relationship between the 5 and 8 Pillars?

Support to people with dementia and their carers

6. How many people have you supported in your role as DPC?

7. Could you give a couple of examples of the ways in which you have worked with someone and what you have done with them?

8. What has changed (if anything) for people with dementia and their carers as a result of your role? What support would they have received in the past?

9. What is distinctive about the needs of a person with dementia that makes the DPC important?

Partnership working

10. Who are the key partners with whom you work regularly?

11. What has been the impact of the test site on the way agencies/partners/ staff work together?

12. How did health and social care work together locally prior to the 8 Pillars? Has the 8 Pillars made a difference to the way in which they work together

Final questions

13. Could I ask about recording data for the dataset supplied by the Scottish Government: has this been straightforward? If not why not? Is it clear what is wanted by way of recording for each Pillar? Should there be more guidance about what is wanted? [*probe for any other views on this*]

14. Have there been any unintended consequences from the 8 Pillars test site? (For example this might be improved diagnosis rates, improved pathway and referral processes, more emphasis on dementia services as a whole, more training/support for staff working with people with dementia.)

15. Do you feel that care is better co-ordinated for people with dementia and that they and their carers feel better supported as a result of the test site/or not? [*Explore the answer*]

Carers

1. Who do you care for? How long have you fulfilled the caring role? How long has the person you care for had a diagnosis of dementia?

2. Are you aware of the DPC role that X (*name the DPC*) undertakes?

3. What support have you received from him/her? What support has the person you care for received? Please give examples of the kinds of thing they have done/helped with.

4. How has it made a difference to you/ the person you care for? *Probe the answer.*

5. *Depending on the answer to Q 1* How does the support you have received from the DPC differ to what was offered before they were in post?

6. What else would help to support you/the person you care for?

7. Is there anything else you would like to add about the support you have received?

Partners(this might be consultants, GPs, Alzheimer Scotland local representative, Link Workers etc)

1. Name, title and role in relation to people with dementia and their carers

2. What contact or involvement have you had with the 8 Pillars test site/the DPC(s)?

3. What is your view on the relationship between the 5 and 8 Pillars?

4. How has the role of the DPC impacted on your work/the way in which you work? *Explore the answer.*

5. From what you have observed, how has the role of the DPC made a difference to people with dementia/their carers?

6. What is the main value of the role of the DPC?

7. What is distinctive about the needs of a person with dementia that makes the DPC role important?

8. How could services and support offered be more effective for people with dementia and their carers?

9. Have there been any unintended consequences from the 8 Pillars test site? (For example this might be improved diagnosis rates, improved pathway and referral processes, more emphasis on dementia services as a whole, more training/support for staff working with people with dementia.)

10. Do you feel that care is better co-ordinated for people with dementia and that they and their carers feel better supported as a result of the test site/or not? [Explore the answer]

11. Any other comment?

Health and Social Care Partnership Manager

1. The context: recap over why they applied (drawing on our first interview)

2. What has your role been in relation to the test site? (*probe: how hands on/ distant, what involvement have you had with things like supervision, involvement in governance*)

3. Management & Governance: *again recap from what we learnt at first visit and check accuracy of the information*. How is the work of the pilot governed and managed? Are there minutes we can look at? How many meetings and what frequency?

4. Data: once we have seen the data from the test sites explore any issues arising from what we have seen.

5. What impact has the test site had on:
   -staff?
   -people with dementia and their carers?
   -the organisation as a whole (if any)?
   - work with partner agencies?

6. Has it influenced the organisation's strategic direction or policies relating to dementia?

7. What is the pilot's scope for scaling up to cover a wider geographical area? Is this something you would like to do? Is this something you plan to do?

8. What is distinctive about the needs of a person with dementia that requires this form of support compared to people with cancer/diabetes/COPD?

9. How are the 5 and 8 Pillars applied in your area? Are there any issues with the distinction between the approaches? How does this impact on the caseload and activity of the DPC?

10. Have there been any unintended consequences from the 8 Pillars test site? (For example this might be improved diagnosis rates, improved pathway and referral processes, more emphasis on dementia services as a whole, more training/support for staff working with people with dementia.)

11. Do you feel that care is better co-ordinated for people with dementia and that they and their carers feel better supported as a result of the test site/or not? [*Explore the answer*]

12. Overall what lessons have been learnt that can help inform the operation of your Health and Social Care Partnership?

13. Any other comments?

Staff (possibly as a group discussion of 3-4 people)

(staff within the organisation where the DPC is based/works)

1. Start with general introductions and names/roles and what work they are involved in with people with dementia and their carers

2. Has the test site/the role of the DPC impacted on your work in any way? If yes how?

3. Do you think the role of DPC has made a difference to people with dementia their carers? In what ways/ if not why not?

4. How could things work more effectively for people with dementia and their carers?

5. What is the value, if any, of having a DPC? What is distinctive about people with dementia that makes having a DPC important (if they agree that it is important)

6. Any comment on the 5 Pillars and 8 Pillars?

7. Have there been any unintended consequences?

8. Any further comment.

APPENDIX 2 –INTERVIEWEES

Glasgow

Project Facilitator

Service Manager NW Locality (Older People and Primary Care) Glasgow City HSCP

Adult Services Manager, Glasgow City HSCP South Sector

CPNs x 5

Occupational Therapist

415 Project manager

Joint Improvement Team support person

Alzheimer Scotland, Policy and engagement manager

Highland

Service Manager for Community Mental Health Services, Chair of Steering Group

District Manager, and NHS Lead

The DPC and Project Manager

The PDS worker in the co-located team

The older adults CPN in the co-located team

Joint Improvement Team support person

One carer

Midlothian

Dementia Project Officer

Single Dementia Team Lead,

Service Manager, Older People at Midlothian Council

Clinical Service Manager, NHS Lothian

CPNs x 2

Social workers x 2

Occupational Therapist

Post diagnostic support worker x 2

Old Age Psychiatry Consultant

Dementia Local Area Coordinator, Volunteer Midlothian

Carer

Moray

Steering Group chair
Project Manager
 Project Assistant
 Seven DPCs
Members of the Steering Group (representing Mental Health directorate, Nursing directorate, Hanover Housing, Quarriers, Alzheimer Scotland)
Partners (Social Work Access Team, Alzheimer Scotland PDS Link Worker, Occupational Therapist, Psychologist, Practice Manager, GP)
Two carers from the 8 Pillars test; one carer from the 5 Pillars programme;five other non-test site carers
Joint Improvement Team support person
Attended a one-day conference on both the 5 Pillars and 8 Pillars approaches early in 2016.

North Lanarkshire

Chair (former) of the Steering Group
Seven DPCs
Service Manager Dementia Practice (Project Lead)
Two Joint Improvement Team support people
Steering Group member, NHS representative (former)
Service Manager-Mental Health, Old Age Psychiatry
Alzheimer Scotland, Policy and Engagement Manager
One carer's diary (directly involved in 8 Pillars) viewed and two carers interviewed (not directly involved in 8 Pillars)