Care co-ordination in the community for people with dementia in Midlothian

Summary of an appreciative inquiry and data analysis to understand the critical success factors

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Executive Summary

Although care co-ordination as a concept is relatively ill-defined and under researched, available evidence suggests that effective care co-ordination can lead to positive outcomes, including fewer hospital admissions and lower medical costs for people with dementia[1].

As part of the 2017 National Dementia Strategy in Scotland, there is a commitment to deliver a more flexible, co-ordinated and person-centred approach to supporting people with dementia in the community from diagnosis to end of life[2].

This work describes an appreciative inquiry and data analysis undertaken in Midlothian Health and Social Care Partnership (HSCP), which has been recognised as delivering such an approach. The key findings of the inquiry are listed below:

- People with dementia have support needs which result in relatively high health and social care resource use, which is consistent with previous findings in Scotland,
- However, the overall resource costs for people with dementia in Midlothian are significantly lower than in other Health and Social Care Partnerships in the NHS Lothian area,
- People with dementia in Midlothian are significantly less likely to die in hospital compared to those in other Lothian areas,
- Data analysis suggests that a higher proportion of people with dementia are diagnosed and identified in Midlothian, compared to other HSCPs in the Lothian area.

This work identified twelve critical success factors to delivering successful co-ordinated care to people with dementia. The success factors related to the existence of a dedicated, proactive, well-trained dementia team with effective work practice and culture (distributed leadership and role blending), that put the needs of carers at the centre with excellent ongoing communication and support to families and carers. Findings from this work will be used to inform future work supporting the delivery of care services for people with dementia and their carers.

1. Introduction and Background

There are estimated to be 90,000 people with dementia in Scotland[3], and the majority of people with dementia are living at home. With numbers of people with dementia expected to double in the next 25 years[4], delivering integrated co-ordinated care has never been more crucial.

Without continuity and co-ordination of care and support, people with dementia, carers and families can experience fragmented, poorly integrated care from multiple providers. Duplication of effort and avoidable hospital admission are often the result[5].

Care co-ordination as a concept is relatively ill-defined and under researched. The World Health Organisation (WHO) defines it as:

> *"a proactive approach to bringing together care professionals and providers to meet the needs of service users to ensure that they receive integrated, person-focused care across various settings."*[1]

Based on a review of published evidence, the WHO suggested that a high level of continuity of care may result in 13% fewer hospital admissions and 27% fewer visits to an emergency department; and that for those with complex needs, continuity of care is a key enabler of co-ordinated care. They also cite evidence that co-ordinated home-based primary care can result in 17% lower medical costs. Similarly, a recent briefing from the Nuffield Trust[6] highlighted that key success factors for integrated care models reducing hospital admission are well-defined team objectives, role definitions and good communication. Those referring to the team should have a clear understanding of its purpose.

The third National Dementia Strategy in Scotland (2017-20)[2] was published in June 2017 and sets out a vision for a more flexible and person-centred approach to supporting people with dementia in the community. The strategy aims to ensure people with dementia and those who care for them have access to timely, skilled and well-co-ordinated support from diagnosis to end of life. Commitment 4 of the strategy states:

> *"We will consider the learning from the independent evaluation of the 8 Pillars project on the benefits and challenges of providing home-based care co-ordination and proactive, therapeutic integrated home care for people with dementia."*[2]

Whilst good practice exists in Scotland, there remains inconsistency and variation in both practice and service provision. In Scotland, people diagnosed with dementia should receive a minimum of one year's post-diagnostic support. However, following post-diagnostic support, in many areas there is not a clear mechanism for people to re-engage with and feel connected to, the health and social care system. It can be difficult for people to navigate the system to obtain the necessary care. Providers of care may also have difficulty communicating

with each other in order to meet the needs of individuals. This can lead to an individual's first contact being at a time of crisis. To support Scotland's second national dementia strategy, 2013-16, Alzheimer Scotland's 8 pillars home-based support model[7] was tested in 5 areas, one of which was Midlothian. The 8 pillars model is a co-ordinated and strategic approach to providing effective, integrated community support to people with dementia and their carers, and at its heart is a Dementia Practice Co-ordinator - a skilled practitioner who identifies needs and co-ordinates appropriate support across organisations[7].

Midlothian HSCP has a dedicated, co-located dementia team which has a single point of access. The co-ordination relationship commences as soon as the person with dementia is referred to and accepted by the team (which requires a suspected and/or confirmed diagnosis of dementia) and lasts until end of life. The partnership was identified as an exemplar site in the 2016 independent evaluation[8] of the Alzheimer Scotland 8 Pillars Model[7] because of the co-ordinated approach of their integrated dementia team. The partnership has attracted much attention from other areas in Scotland and internationally, to learn how they have sustained this approach to integrated care co-ordination for people with dementia and their carers.

A combined methodology of appreciative inquiry and quantitative analysis of routinely collected data was used in order to better understand the concept of care co-ordination and its benefits. The inquiry and analysis sought to understand:

- the care co-ordination approach in Midlothian and the impact on outcomes for people with dementia, their carers and staff, and
- the critical success factors associated with the Midlothian approach.

It is hoped that the findings from the inquiry can be used to inform future planning and service design for NHS boards, and health and social care partnerships (HSCPs), as well as future work to support the implementation of National Dementia Strategy commitments across Scotland.

This report sets out the methodology and findings from the appreciative inquiry and data analysis carried out within Midlothian HSCP.

2. Methods

Focus on Dementia, part of Healthcare Improvement Scotland's Improvement Hub (ihub) formed a multi-agency working group, which included representatives from Alzheimer Scotland, NHS Education for Scotland, Scottish Government, NHS Public Health Scotland (formally Information Services Division) and Midlothian HSCP staff to design an approach to include quantitative data analysis and qualitative analysis using an appreciative inquiry approach.

Quantitative Analysis

Public Health Scotland (formally NHS Information Services Division (ISD)) undertook an analysis of health and social care information from 2017/18 to see how people with dementia accessed services in Midlothian and the other HSCPs in the NHS Lothian area. The data sources used were: NHS Lothian's electronic patient management system (TrakCare), the Public Health Scotland Source dataset and social work data. For the purpose of the analysis 'people with dementia accessing services' were defined as people accessing services within the NHS Lothian area with a recorded diagnosis of dementia on one or more of the data sources. The analysis compared:

- recorded prevalence of dementia with estimated prevalence (based on Alzheimer Scotland's dementia prevalence analysis[3], stratified for local population demographics),
- the pattern of service usage and associated service costs for people with dementia in Midlothian (as defined above) with that in the other HSCPs in the NHS Lothian area; No assumptions were made about the quality of the dementia services in these areas compared with Midlothian,
- the use of health and social care services by people with dementia and those without dementia in order to contribute to a better understanding of the respective service needs of those populations and to inform local service planning,
- unplanned admissions in the last 3 months of life and place of death for people diagnosed with dementia compared with people without a diagnosis of dementia for Midlothian and the other HSCPs in the NHS Lothian area.

In addition, patient journeys across health and care services in Midlothian were mapped using a commercial process mining tool called Celonis. This tool shows the complexity of patient journeys and provides a more detailed understanding of service utilisation, which may contribute to forward planning for health and social care service delivery.

Appreciative Inquiry

In order to better understand how care co-ordination works in practice in Midlothian, Focus on Dementia commissioned the qualitative analysis, which was conducted by an independent Improvement Associate. Individual interviews and focus group sessions were held with the dementia team in Midlothian and representatives of relevant third sector organisations to understand team structure, ways of working and culture and to review the care pathways for people with dementia. Qualitative feedback from people with dementia and their carers who were recent recipients of support from the dementia team was also considered. The McKinsey '7S' model[9] was used as a framework for the qualitative analysis to consider the three 'hard' elements (strategy, structure and systems) along with four 'soft' elements (skills, staff, style and shared values) of the organisation.

3. Quantitative Findings

3.1 Dementia Prevalence

Table 1 shows the population of Midlothian with the estimated and actual numbers of people with a recorded diagnosis of dementia (sourced from Alzheimer Scotland modelling[3]), compared to the rest of NHS Lothian and to the all-Scotland figures. These figures can be further divided to show male/female numbers and over/under 65 age profiles; however for simplicity only the overall figures are included.

Ideally everyone who has dementia would have access to timely assessment and diagnosis, in order to facilitate appropriate care, support and (where appropriate) treatment. In practice, this is an aspiration. Many countries have developed strategies to improve diagnosis rates, and Scotland has had a programme of work aimed at this since 2009 which was monitored through a HEAT target. This HEAT target stated: "Each NHS Board will achieve agreed improvements in the early diagnosis and management of patients with a dementia by March 2011."[10]

The data suggest that Midlothian has a higher percentage of people diagnosed with dementia than the rest of NHS Lothian and Scotland. Knowing which of its citizens have dementia, and how they use services, facilitates provision of appropriate care and support as well as planning for future services.

Table 1 Dementia prevalence

	Total population	**Number of people with a recorded diagnosis of dementia**	**Estimated prevalence (number of people with a diagnosis of dementia) based on Alzheimer Scotland modelling**	**% prevalence (proportion of people with a recorded diagnosis compared to estimated number of people with dementia)**
Midlothian HSCP	90k	1,218	1,452	84%
Other HSCPs in Lothian area	770k	8,931	12,137	74%
Scotland	5,450k	69,109[11]	93,551	74%

3.2 Service use and associated service costs for people with dementia compared to people without dementia in Midlothian

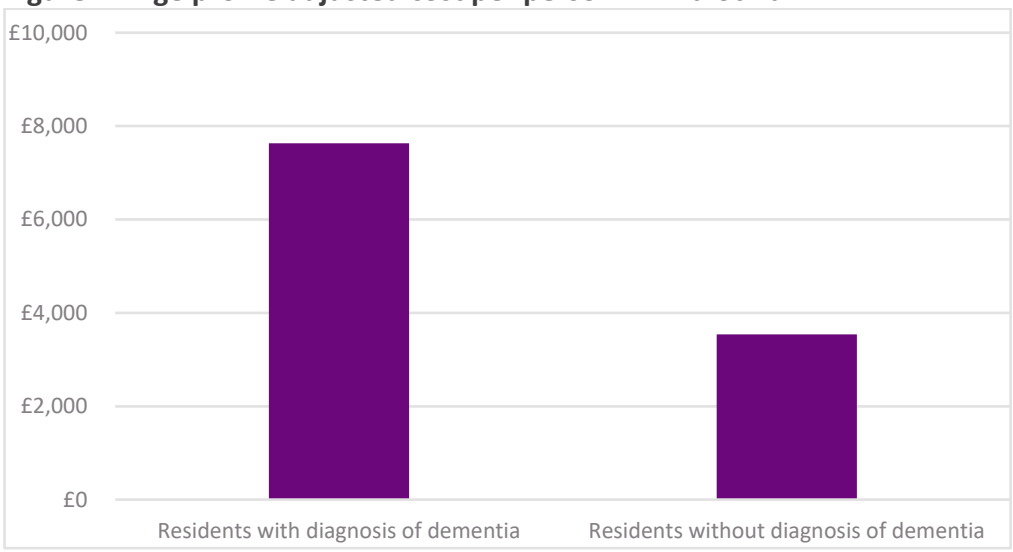
Table 2 summarises the resources used by people with a diagnosis of dementia in Midlothian compared to those without dementia. When the data are further refined to extrapolate resource use for over 65s - a more meaningful comparison than all ages - there is a marked difference in the amount of resource consumed by someone with dementia (Figure 1; table 3).

Table 2 Service utilisation in Midlothian

	People with a diagnosis of dementia	**People without a diagnosis of dementia**	**People without a diagnosis of dementia aged over 65**
Total spend on services*	£9.32m	£92m	£55m
Number of people	1,218	88,782	15,522
Average spend per person	£7,651	£1,036	£3,541

*To calculate this, data on Midlothian residents was obtained from NHS Lothian's TrakCare and Public Health Scotland's Source dataset as indicated on p7.

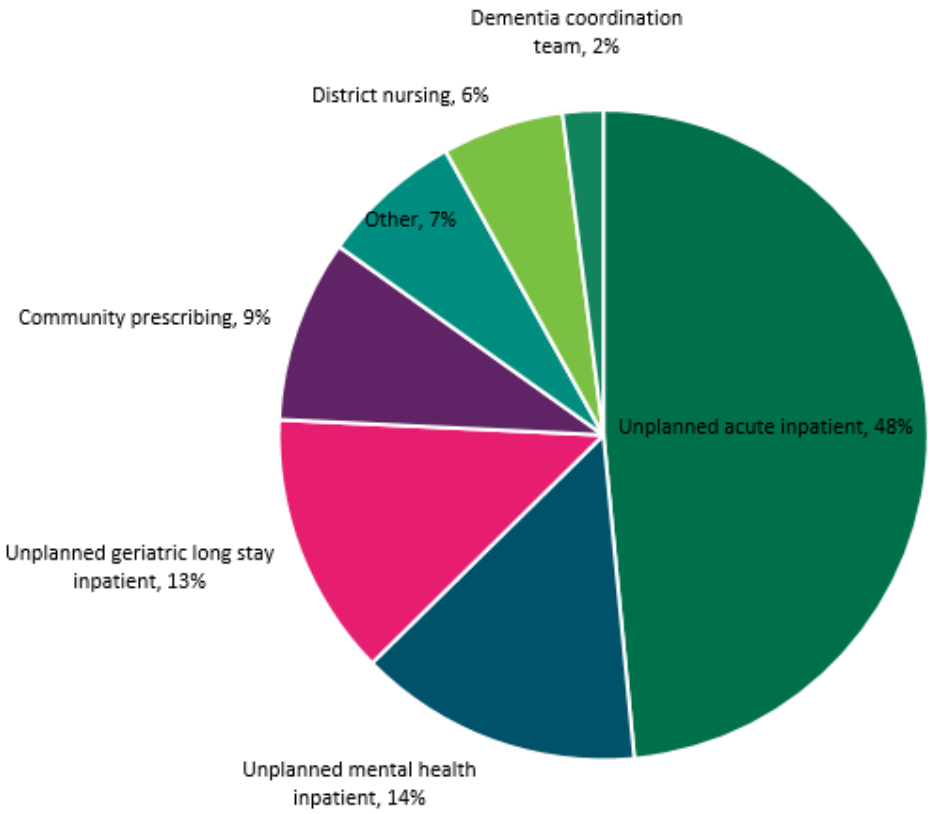
Figure 1: Age profile adjusted cost per person in Midlothian



In keeping with all-Scotland findings[12], 50% of the resource use by the Midlothian population is accounted for by just 2% of the population. People with dementia (1.4% of the population in Midlothian) account for 13% of these individuals. This is important as a basis for service planning and improvement; and especially so for a care group for whom prevalence is projected to increase significantly over the next twenty years.

A detailed breakdown of resource use for Midlothian residents with a diagnosis of dementia (Figure 2) shows that almost half of spend is on unplanned acute inpatient care.

Figure 2: resources used to support people with dementia in Midlothian



Note 2: Percentages do not total 100 due to rounding

3.3 Service use of people with dementia in Midlothian compared to people with dementia in the other HSCPs in the Lothian area

Figure 3 and table 3 illustrate resource use by people with dementia in Midlothian £7,498 (CI £6,734, £8,263 per person) compared to people with dementia in the other HSCPs in the Lothian area £8,747 (CI £8,375, £9,119 per person). The overall spend per person is significantly lower in Midlothian.

Figure 3 Resource use - comparison between Midlothian and other Lothian HSCPs

Note: excludes spend on Midlothian dementia co-ordination team as this information not available for all HSCPs in the NHS Lothian area but figure 2 illustrates that this spend forms only a small proportion of the total spent.

Table 3 Service utilization people with dementia

	Midlothian (people with a diagnosis of dementia)	**Other HSCPs in the Lothian area (people with a diagnosis of dementia)**	**Significance**
Average spent per person	£7,498 (CI £6,734, £8,263)*	£8747 (CI £8,375, £9,119)	Significant
Geriatric long stay bed rate (average bed days per person)	4.6 days (CI 3.0, 6.2)	2.1 days (CI 1.7, 2.6)	Significant
Acute inpatient bed day rate (average bed days per person)	8.7 days (CI7.6, 9.9)	12.2 days (CI 11.5, 12.8)	Significant
Average acute hospital length of stay	15.9 days (CI 14.1, 17.8)	21.3 days (CI 20.3, 22.3)	Significant
Time spent as a delayed discharge as a percentage of total delayed discharge time (i.e. people with and without a diagnosis of dementia)	46%	45%	Not Significant

***Confidence Interval (CI) were calculated and used to determine statistical significance. When confidence intervals do not overlap, this indicates that there is a statistical significance between two groups.**

3.3.1 Hospital bed use

Compared to the other HSCPs in the Lothian area, there was significantly higher use of geriatric long stay beds for people with dementia in Midlothian, at 4.6 days per person compared to 2.1 days. Reduced costs were mainly due to shorter inpatient stays in acute hospital, compared to the other areas. For acute specialties, the Midlothian bed day rate for people with dementia was 8.7 bed days per person, significantly lower than 12.2 per person in the other areas.

People in Midlothian with dementia who are admitted to an acute hospital have a significantly lower average length of hospital stay: 15.9 days compared with 21.3 days for the other HSCPs in the NHS Lothian area. This is clearly a benefit to people with dementia, particularly given that when people with dementia are admitted to acute care they are more likely to have adverse outcomes such as falls, pressure ulcers and infections[13].

3.3.2 Delayed discharge

Delayed discharge continues to be an issue across all of the HSCPs in the NHS Lothian area. People with dementia account for 46% of delayed discharge time in Midlothian. This compares to 45% in the other Lothian HSCPs. Requirements of the Adults with Incapacity (Scotland) Act (2000) which ensures due process when discharging an individual from hospital who does not have capacity for the decisions needed to facilitate a safe transition from hospital, accounts for 4.4% of delayed discharge in Midlothian. Future work is required to understand other significant factors which are having the greatest impact on delays. Since the inquiry started, Midlothian have now invested in a Discharge to Access (D2A) service, which works closely with third sector services to support individuals to have a timely discharge from hospital and provide them with assessment and rehabilitation in their own homes.

3.4 End of life care

Table 4 illustrates the similarities and differences for people who died in 2017/18, with and without dementia, across HSCPs in the NHS Lothian area. Unplanned admission rates for people with dementia in the last 3 months of life were similar across all of the HSCPs. Whilst unplanned bed day rates and average length of stay for people with dementia were lower in Midlothian in the last 3 months of life, this was not significant. However, a significantly smaller proportion of people with dementia who died in Midlothian died in hospital than in other Lothian partnerships.

Whilst this work cannot, with any certainty, attribute the differences between Midlothian and the other Lothian HSCPs to the Midlothian dementia team and care co-ordination approach, the data suggests that there are differences in how people with dementia in Midlothian use health and social care which are worth further exploration in future work.

Table 4 End of life care last 3 months of life

	People with a diagnosis of dementia in Midlothian	People with no diagnosis of dementia in Midlothian	People with a diagnosis of dementia in other NHS Lothian HSCPs	People with no diagnosis of dementia in other NHS Lothian HSCPs	Significance
Number of people who died	260	582	n/a	n/a	n/a
Unplanned Admission Rate	0.67 (CI 0.57, 0.77)	1.08 (CI 1.0, 1.17)	0.68 (CI 0.64, 0.71)	1.03 (CI 1.01, 1.06)	No significant difference
Unplanned bed day rate	16.3 (CI 11.8, 20.8)	16.4 (CI 13.4, 19.4)	18.6 (CI 16.8, 20.3)	16.1 (CI 15/1, 17.1)	No significant difference
Average length of stay	24.8 (CI 19.7, 30)	n/a	27.4 (CI 25.4, 29.4)	n/a	No significant difference
Percentage of people who died in hospital	36.1 (CI 30.0, 42.2)	n/a	49.8 (CI 47.8, 50.2)	n/a	Significantly lower in Midlothian

***Confidence Interval (CI) were calculated and used to determine statistical significance. When confidence intervals do not overlap, this indicates that there is a statistical significance between two groups.**

3.5 Patterns of service use by people with dementia

Appendix 1 contains a visualisation of the way people with dementia over the age of 65 in Midlothian moved into and out of services, including pathways between home/care home and hospital. It has not been possible to show every pathway or service utilised due to the limitations of the dataset, and also because the resulting diagram would be too complex to facilitate interpretation. However, understanding the patterns of service use, including the extent to which people move - or more accurately, are moved - around the system supports the HSCP to better manage patient journeys and to plan future services. This pathway also demonstrates the complexity of service use, with individuals often experiencing multiple moves.

4. Qualitative Findings

The findings from the appreciative inquiry have been split into three levels of care co-ordination (micro, miso and macro), as defined by WHO[1], and feature staff quotes from the focus group sessions. The findings have informed a set of recommendations for other HSPCs at each level.

Macro – Organisation level - system enablers to facilitate care co-ordination

> *"Senior managers have made themselves accessible to people in public forums. People can see that their voice is being heard"*

Whilst Midlothian HSCP does not have a specific strategy for dementia, there is a dedicated section in their current strategic plan[14]. In addition, there are frequent references to dementia within the main body of the plan (63 references in total) suggesting the partnership sees dementia as a key priority and takes an inclusive and integrated approach in the commissioning, planning and delivery of services.

In 2015, Midlothian HSCP ran a series of commissioning events with voluntary sector organisations in the region. The aims were to identify the needs of people with dementia, the services currently delivered, the gaps and how they could be addressed.

With Midlothian HSCP acting as the co-ordinator (system enabler), the voluntary organisations were encouraged to collaborate with each other in creating a menu of services. The process was facilitated in a way that encouraged collaboration between the different providers rather than competition. Service users were actively involved in these sessions, which meant the needs of the local population were held in the forefront of discussions. Fostering co-operation between services underpins the co-ordination of care, ensuring that people are supported to access the right services at the right time to meet their needs.

From a strategic standpoint, the needs of carers are seen to be equally as important as those of people with dementia. The Carers (Scotland) Act which came into effect on 1st April 2018, was implemented in Midlothian using the following approach:

- Funding to Alzheimer Scotland specifically for carer support was continued,
- A carers' organisation called VOCAL is supporting an increasing number of carers with emergency plans if they were suddenly taken ill/or unable to cope,
- Supporting the Dementia Cafes in Midlothian to expand the number of groups by providing free venues,

- Workshops have been provided to front line staff on improving their skills in carer assessments.

As a result of these interventions Midlothian is seeing:

- Increased numbers of carer assessments completed by VOCAL, Social Workers and Occupational Therapists (OTs),
- Increased numbers of carers applying for funding from the council following carer assessment and using flexibly to access regular support/respite,
- Social Workers and OTs being more imaginative by exploring a range of respite options.

In addition, an annual public consultation event ensures that the HSCP strategy is built on what the people of Midlothian have told them.

> *"Keeping people at home is the default, so carer enablement, resilience and support including peer support is a significant part of the Midlothian service"*

Meso - Service level - defined care pathways and single integrated point of access

The single point of access to the Dementia Team is the cornerstone of co-ordination at a service level. The team holds the caseload of everyone with a diagnosis of dementia in Midlothian. A team secretary ensures timely communication between families and the relevant member of the dementia team and a weekly meeting ensures effective co-ordination of care and support. The makeup of the core team is detailed in table 5.

Table 5 Midlothian dementia team staff resource

Role	Number
Team Leader	1
Consultant Psychiatrist	2 (1.7WTE)
Community Psychiatric Nurse (CPN)	5
Healthcare Support Worker	1
Social Workers	3
Occupational Therapists	2
Community Care Assistant	1
Dementia Team Secretary	1 (0.5 WTE)
Alzheimer Scotland Dementia Link Worker	3 (2.0 WTE)

"There's a link worker for every family"

There are periods when no input is required from the Dementia Team and the person is ostensibly 'discharged'. However, they are provided with information about how they or their family can self-refer directly back to the team rather than going through their GP.

"We try not to use the word 'discharge'; the team is always there"

A significant contribution is made by third sector organisations in sustaining families at home. There is also a good working relationship between non dementia-specific third sector providers and the team. This enables early intervention for anyone attending general day services or community activities who the staff suspect may be developing signs of cognitive impairment.

"There's a balanced tolerance of risk; the team is very respectful of everyone's views"

As well as well-defined roles there is also a sense that each team member's contribution is important and that staff feel valued. There appears to be a high degree of 'psychological safety' in Midlothian HSCP which Edmonson[15] identifies as "unconditional positive regard and personal safety".

"There's an absence of competition between agencies or if there is any, it's a healthy competition"

Team members are outward and forward looking and are continually alert to where systems and processes could be improved to provide better quality services and have undertaken quality improvement initiatives to drive improvement. These have included streamlining their dementia clinics to allow them to see the same number of people in two clinics as had been seen in six, and improving triage to post-diagnostic support, resulting in more timely access to post-diagnostic support for people with a new diagnosis of dementia.

All staff in the dementia team are trained to 'Enhanced' level of the Promoting Excellence Framework[16]. A Dementia Specialist Improvement Leader who has 'trained as a trainer' is a core member of the team and takes some of the responsibility for providing 'in-house' dementia-specific training in Midlothian. Outreach training is also provided to care home staff in the area.

In addition to dementia-specific training, the team leader, a Consultant Psychiatrist and an Occupational Therapist have been trained in improvement methodology through the NHS Lothian Quality Improvement Academy.

> *"We model empowerment within the HSCP and that's how we approach the person with dementia…."*

Despite electronic information systems creating some barriers, especially for the third sector, the dementia team works around these to promote the best possible lines of communication.

There is a sense of the core dementia team acting as a co-ordinating hub in Midlothian with a number of satellites in the wider community created by the third sector organisations. This networked human system enables two-way flow of information promoting deep understanding of dementia throughout the community.

> *"Good relationships and communications across health and social care and 3rd sector compensate to an extent for absence of shared systems"*

> *"The team being co-located makes for easy dialogue"*

Micro - Individual level - the relationship between the family and the care co-ordinator

From the first point of contact, the team is proactive in promoting independence and quality of life. For example, families are supported to access legal advice to establish Power of Attorney and are provided with advice on benefits maximisation. Self-directed support (SDS) is being considered much more for people with dementia. SDS allows people, their carers and their families to make informed choices on what their support looks like and how it is delivered[17]. There are 16 people with dementia in Midlothian receiving SDS on option 1 (where you choose to receive a direct payment to purchase support yourself) or 2 (where the council gives you the option to choose your own support while it holds the money and

arranges the chosen support on your behalf). This is instead of the traditional option 3 where the council selects and arranges the support.

> *"The team is the co-ordinator. There's a stickiness to the client. The team as a whole will be very close to a person's story"*

The needs of carers are seen to be paramount in enabling people with dementia to live well at home. Sustained, responsive support is provided over time from a network of professionals and support organisations. Information sessions are also offered to informal carers in a group setting. Topics include psychological care for carers and how to prevent stress and distressed behavours.

> *"VOCAL being based at the Midlothian Community Hospital Memory Clinic enables us to pick up referrals at early/initial stages of diagnosis"*

5. Recommendations

Drawing on both the quantitative and qualitative findings, the following recommendations are designed to support HSCPs to deliver a care co-ordination approach for people with a diagnosis of dementia, in order to provide person-centred and outcomes-focused care and also ensure the most efficient and effective use of resources.

Macro level recommendations

- Given the significant use of resources by people with a diagnosis of dementia, a strategic focus on services for people with dementia is essential, especially because this is a group for which prevalence is projected to increase substantially over the next twenty years. As illustrated by the data, people with dementia have relatively complex support needs that may be mitigated by effective whole-system care co-ordination.

- This paper suggests that effective co-ordination supports more efficient use of resources, therefore HSCPs should ensure that this is reflected in the strategic direction.

- Senior HSCP managers should maximise their role as 'system enablers' in harnessing the unique contribution of third sector organisations through effective commissioning and co-ordination on a community-wide basis, and in supporting efficient and effective processes that enhance co-operative working across teams and sectors.

Meso level recommendations

- HSCPs should consider establishing a dedicated dementia team approach with a clearly identified leader and administrative support for co-ordination.

- Distributed, empowering leadership is fundamental to creating a respectful team culture that is inclusive and quality driven.

- Training and development in improvement methodologies should be part of the dementia team's CPD curriculum as well as knowledge and skills in dementia care.

- Regular multi-agency planning and review meetings and proactive intervention in support of carers to avoid a breakdown in care arrangements should be championed as the hallmarks of effective care co-ordination.

Micro level recommendations

- Effective care co-ordination requires a respectful partnership approach between people with dementia, their carers and the dementia team.
- An explicit focus on providing support and guidance for carers is essential to supporting people with dementia to remain at home.
- The support offered to people with dementia should be personal, outcomes-based, responsive and proportionate to their needs. An incremental approach is recommended, so that support is tailored to the stage of readiness as well as the stage of illness.

6. The Critical Success Factors

The following 12 critical success factors to delivering successful care co-ordination support to people with dementia have been extrapolated from this work. Many of them will be in evidence across other partnerships in Scotland but clearly it is a mix that has worked well for Midlothian.

1. There is one dedicated dementia team for the partnership population with a single point of access and an identifiable leader.

2. The team is proactive in promoting independence and quality of life for people with dementia from diagnosis to end of life.

3. The needs of carers are a central focus to sustain families living at home.

4. After a period of independent living, families can self-refer directly back to the team as home circumstances begin to change with disease progression.

5. A weekly team meeting ensures effective co-ordination of care and support.

6. The prevailing culture is one where each team member's contribution is seen as important and staff feel valued. The roles within the team are well-bounded minimising competition and preciousness.

7. A significant contribution to the effectiveness of care co-ordination is made by third sector organisations.

8. All staff are trained to an enhanced level of knowledge and skills in dementia and offer training to carers, care homes and the local community to build an informed and compassionate response to people living with dementia.

9. Team members are outward and forward looking and are alert to where systems and processes could be improved to provide better quality services.

10. There is a whole system philosophy of enabling, distributed leadership, a commitment to integration and to providing the best possible care for people with dementia and their families.

11. Care co-ordination occurs at micro, meso and macro levels. Middle and senior management see it equally as their role to enable best practice by having the right systems in place.

12. An effective two-way flow of information between individuals and services promotes a deep understanding of dementia throughout the local community and in turn, dementia-friendly, risk tolerant ‘watchfulness’ within the wider community enables early intervention.

7. Conclusions

This inquiry sought to explore and understand Midlothian's approach to care co-ordination in the community for people with dementia and their carers. It confirms Midlothian's position as an exemplar, demonstrating the benefits which can be achieved for people with dementia and to the costs of delivering services through a care co-ordination approach.

This inquiry found that people with dementia have support needs that result in high health and social care resource use, which is consistent with the national picture for Scotland. However, the overall resource costs for people with dementia in Midlothian are significantly lower than in other HSCPs in the NHS Lothian area. The main differences are in the cost of inpatient stays in acute and psychiatric specialties despite the higher use of geriatric long stay beds. People with dementia in Midlothian are also significantly less likely to die in hospital. Midlothian was also shown to be better at identifying people with dementia than the national average.

Whilst the findings in this paper cannot absolutely attribute the differences between Midlothian and the other Lothian HSCPs to the dementia team and the care co-ordination approach, there do seem to be differences in how people with dementia in Midlothian use health and social care which is worth further exploration in future work looking at care co-ordination. It would be of interest to undertake a further analysis incorporating the cost of the team against models in other areas.

There was strong evidence of positive leadership behaviours, effective use of quality improvement methodology in practice, high levels of dementia knowledge and skills by staff, robust communication mechanisms, effective multi-agency working and a partnership approach between people with dementia, carers and the team, which all contributed to the effectiveness of the service.

Given the growing prevalence of older people in our communities, HSCPs should consider dementia a priority for strategic planning and service delivery.

Twelve critical success factors have been identified and whilst these may not be unique in themselves, it is the blend that seems to be the winning formula. The multi-level commitment in particular is critical to success, and points to the need for other health and social care organisations to consider how conditions for success can be created across the three care co-ordination levels of macro, meso and micro.

As well as supporting dementia strategy development work in Midlothian HSCP, the findings from this work will inform further development in dementia services in Scotland. Moreover, by extrapolating the critical success factors and sharing them with other health and social

care organisations, there is an opportunity to inspire improvements in care co-ordination across Scotland and beyond.

The data reinforce previous analysis of health and social care data which found people with dementia to require higher levels of support, dementia being the condition with the greatest risk ratio in the group of individuals with higher support needs[12]. This is important as a basis for service planning and improvement; and especially so for a care group for whom prevalence is projected to increase significantly over the next twenty years.

8. Recommendations for Further Inquiry

- Develop a greater understanding of the number of people diagnosed with dementia through the use of robust coding/registers.
- Continue to use data analysis and pathway mapping to understand how people use services and how we can improve experience and outcomes for people with dementia and their carers.
- Once people with dementia are admitted to hospital they are more likely to experience a delay in their discharge, despite the access to excellent dementia services in the community. Future work should seek to identify the factors that have a bearing on delays and the interventions that could have the greatest impact on avoiding delays.

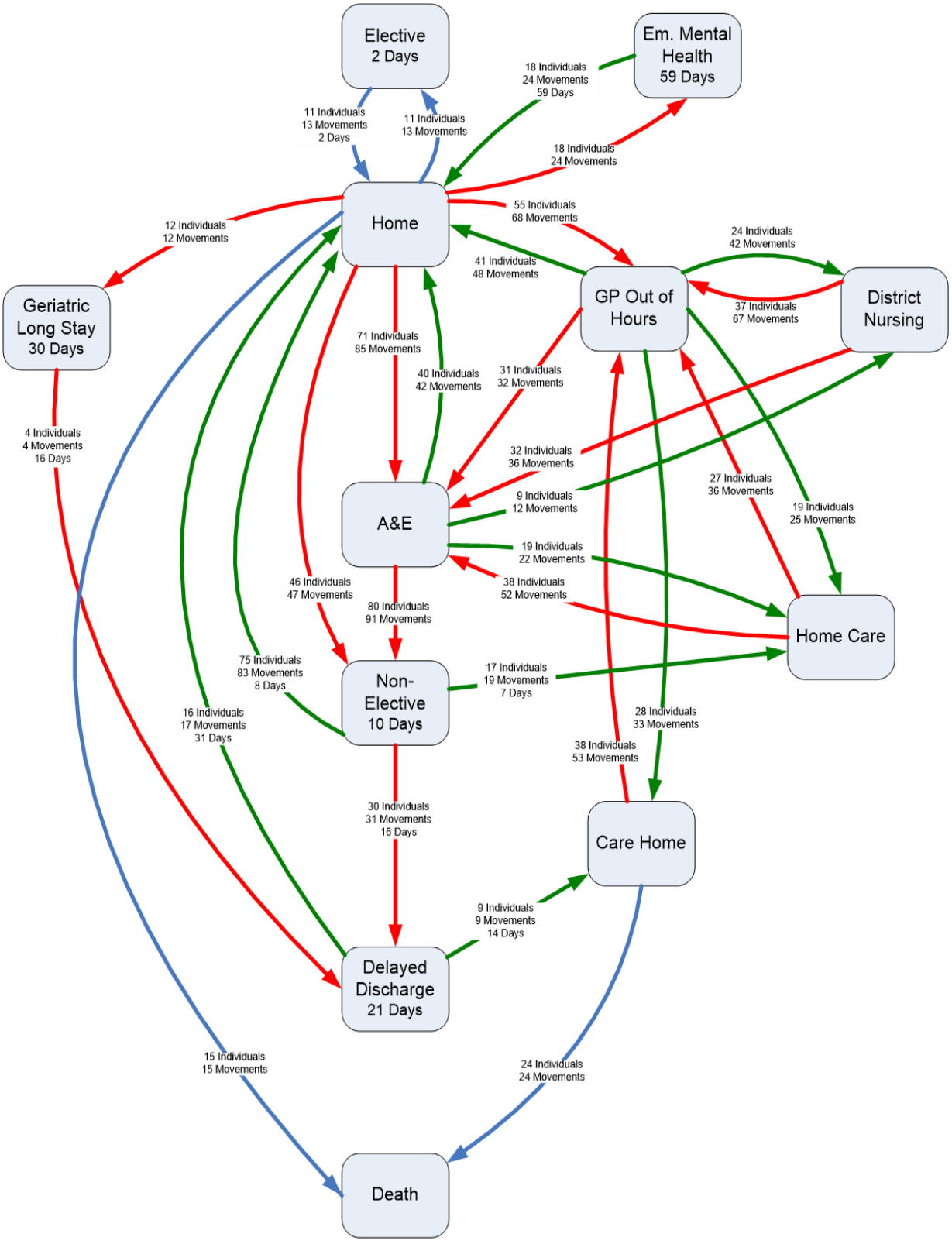
Appendix 1: Patient Journeys

Process mining software was used to map patient care and support journeys for the cohort of people with dementia in Midlothian.

Services used by people living with dementia in Midlothian in one quarter of 2018 were analysed. There are 406 patient journeys included in the pathway. Figure 1 shows an overview of the patient journeys. To simplify these pathways, some lesser-followed pathways have been removed. This is why some numbers going to and from events may not add up correctly.

In the diagram, the main journeys can be observed. There are four main starting points: at home unsupported; at home with district nursing support; at home with a home care package; and in a care home.

Figure 1: 2017/18 Midlothian dementia pathways quarter 4 2017/18



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