Independent Evaluation of the Dementia Fellowship Programme

May 2017

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Section One- The Dementia Fellowship Programme and the Evaluation

This report is organised into five sections and eight chapters.

Section One - The Dementia Fellowship Programme and the Evaluation

Chapter 1: Introduction to the Dementia Fellowship Programme and to the evaluation

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Chapter 2: Overview of Participants and their experience of the Fellowship

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Chapter 1: Introduction to the Dementia Fellowship Programme and to the evaluation

Between 2014 and early 2017, 102 healthcare professionals from across Kent, Surrey and Sussex took part in the Dementia Fellowship Programme, an innovative, modular course integrating clinical learning, leadership and service change. The Fellowship was commissioned by, and developed collaboratively with, Health Education England, Kent Surrey and Sussex (HEE KSS), The Centre for Dementia Studies at Brighton and Sussex Medical School (BSMS) and Sussex Partnership NHS Foundation Trust in 2013. It was led and delivered by Professor Sube Banerjee (SB), Professor of Dementia, Associate Dean and Director of the Centre for Dementia Studies, and Breda Flaherty (BF) BSMS Programme Director for Healthcare Leadership and Commissioning.

After the first three cohorts, the programme leaders commissioned an independent evaluation to capture the impact on those who had attended, both on their knowledge and behaviour as individual practitioners, and on the services in which they worked. Jane Carrier and Dr Edana Minghella were appointed to carry out the evaluation, the fieldwork for which took place between June 2016 and April 2017.

The programme has been delivered to four multidisciplinary cohorts of General Practitioners (GPs), Nurses, hospital doctors, therapists, pharmacists and commissioners.

This report presents the findings from the evaluation of cohorts 1, 2 and 3.

Background to the Kent, Surrey and Sussex Dementia Fellowship

The national policy context

The national dementia strategy, **Living well with dementia: A National Dementia Strategy**,[1] which was published in 2009, raised the national profile of dementia. A number of studies and national reports had already drawn attention to the poor care and outcomes experienced by people with dementia, but the strategy was the first comprehensive national initiative to attempt to tackle these shortcomings. It aimed to raise awareness, tackle stigma, improve diagnosis rates and increase the range of services available to people with dementia and their carers.

Two subsequent initiatives - the **Prime Minister's Challenge on Dementia[2]** published in 2012, and the **Prime Minister's Challenge on Dementia 2020[3]** (launched in 2015) - focused on boosting research, improving care and raising public awareness.

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[1] Department of Health. Living well with dementia: A National Dementia Strategy. Leeds: Older People and Dementia Branch; 2009.

[2] Department of Health. Prime Minister's Challenge on Dementia – Delivering major improvements in dementia care and research by 2015. Leeds: Social Care Policy – Older People & Dementia Team; 2012.

[3] UK Government. Prime Minister's Challenge on Dementia 2020. London: Department of Health; 2015.

The national policy context (continued)

Diagnosis rates for dementia have historically been low, meaning many people have not received the information, support, care and treatment they need to manage their condition. In 2010/11, in England less than half (42 per cent) of those estimated to have dementia had been diagnosed. Since then, rates have increased significantly, and in March 2016, the National Clinical Director for Dementia and Older People's Mental Health announced that the diagnosis rate in England had reached 67%. **The Government's Mandate to the NHS for 2016-17**[4] now includes specific objectives on dementia, notably improving diagnosis rates and increasing the number of people receiving a diagnosis within six (6) weeks of referral, as well as improving the quality of post-diagnosis treatment and support.

Supporting the national policy imperatives is the **Dementia Core Skills Education and Training Framework**[5], which was commissioned and funded by the Department of Health and developed in collaboration by Skills for Health and Health Education England in partnership with Skills for Care in 2015. The framework aims to ensure that all staff working in the National Health Service (NHS) and social care should be able to access training on dementia at the appropriate level for their role.

The Health Education England Kent Surrey Sussex response

Dementia represents a significant challenge for Health Education England Kent, Surrey and Sussex (HEE KSS), as the region has the oldest population of any UK region. The number of people aged 65-84 will increase by 33% and those aged 85+ will double by 2030. The number of people with dementia is forecast to grow by up to 50% by 2030 across the region[6]. Dementia diagnosis rates, however, have been among the lowest of the English regions. For HEE KSS there is therefore an imperative to ensure that staff have the knowledge and skills to detect and diagnose dementia and to deliver high quality care and support.

Against this backdrop, dementia was identified as one of the priority programmes in HEE KSS's **Skills Development Strategy, 2013-2018**[7]. It sets out three priority areas for improvement: diagnosing dementia at an earlier point; improving the quality of care; and reducing avoidable hospital admissions in dementia. A series of stakeholder events in 2013/14 helped to shape four complementary workforce development themes that together make up the HEE KSS dementia programme, of which theme 3 – empowering professionals in practice – underpinned the commissioning of the Dementia Fellowship.

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[4] UK Government. The Government's mandate to NHS England for 2016-17. London: Department of Health. 2015.

[5] Skills for Health and Health Education England in partnership with Skills For Care. Dementia Core Skills Education and Training Framework. London: Department of Health. 2015.

[6] Department of Health. Living well with dementia: A National Dementia Strategy. Leeds: Older People and Dementia Branch; 2009.

[7] Health Education England Kent Surrey and Sussex. Skills Development Strategy. UK: Kent, Surrey and Sussex. Year unknown.

Overview of the Dementia Fellowship

The Dementia Fellowship team

The explicit programme design intention was to offer an integrated clinical and development expertise in the Dementia Fellowship team. This offer to participants was grounded in lived experience of dementia (Table 1), and focused on strengthening what participants could actively lead, act on, and do to improve their own and wider services for patients and carers. The expertise represented within the team was expanded through the inclusion of additional expert contribution from external speakers (see Appendix A). A multi-agency Programme Board was set up to oversee the dementia programme as a whole. The Board's purpose was to provide co-ordination and advice to all elements of the programme in line with the vision and delivery plan and to act as a channel for communication to all stakeholder groups.

Table 1 - The Dementia Fellowship team

Team members	**Key areas of expertise**
Professor Sube Banerjee (SB)	Professor of Dementia Studies at BSMS, focused on offering participants national and international policy perspectives, expertise in the clinical practice of good dementia care, and on developing medical leadership.
Breda Flaherty (BF)	Leadership development and change management expertise, focused on enabling participants to develop their authority to act to change their daily clinical practice, the organisation of services, and to have influence at a strategic level on wider care pathways and health systems.
Vikki Pearce (VP)	Project management and service improvement expertise, focused on enabling participants to initiate service improvements using proven methods and models, to assess impact, and to embed good initiatives in daily practice.
Pippa Gough (PG)	Leadership development and change management expertise, lived experience of dementia care; focused on developing nursing leadership, and bringing a third sector perspective from service users and the Alzheimer's Society into the heart of the programme.
Victoria Hare (VH)	Manager of the Centre for Dementia Studies, project managing the HEE KSS dementia improvement initiatives to ensure connections across the four local work streams.

Overview of aims, structure and content

The aims of the Dementia Fellowship were:

- **To improve people's clinical knowledge-base, and sense of competence and confidence, as clinicians and practitioners offering dementia care**

- **To improve people's ability and confidence to lead clinical or service improvements for people living with dementia**

- **To improve people's awareness of and ability to use change management and service improvement approaches to improve local dementia care**

The Programme comprised four modules, approximately four to six weeks apart. Some modules were two days in length, and Fellows had the option to stay overnight (residential modules).

Each of the three cohorts of the Dementia Fellowship Programme included several core elements, including clinical and best practice content led by SB, leadership, organisation and influence content led by both BF and PG, service improvement models and tools led by VP, and lived experience content led by PG. All of the project team were skilled in offering aspects of each other's lead areas, enabling the team to operate in an integrated way to support participants' learning. The module themes were:

- Good practice in dementia care – nationally and internationally
- Person-centred dementia care – assessment and screening
- Care after diagnosis – changing practice

The Dementia Fellowship team applied a number of underpinning principles to the design of the programme, including the following:

- An evidence-based approach rooted in models of best practice in clinical care, and in well-evidenced material on leadership and change management in improving health services

- A key design principle was to operate with sufficient flexibility and responsiveness to meet the emerging needs of the Fellows, as their knowledge of dementia care and skills in leading change developed over the course of each cohort, and between cohorts

- The programme design was deliberately multidisciplinary, with a strong emphasis on participants improving their mutual knowledge about each other's disciplines, care challenges, and ways of working

- The programme set out to grow supportive networks across the disciplines, showing professionals the potential benefits for patients of sharing learning with each other about good care

- The programme also sought to engage participants in the sometimes emotional and often deeply affecting experiences of living with dementia, seeking to build a trusted learning environment where professionals would feel able to share some of the challenges and rewards in caring well for people living with dementia, and their families

- The focus overall was on building a collective movement for change within the region; this drew on emerging thinking on the role of social movements in improving health, which the Chief Executive of Alzheimer's Research UK has noted in relation to dementia:

  "Since the first Prime Minister's Dementia Challenge was launched we've seen real progress in the fight against this devastating condition, and the beginnings of a social movement to rally people behind that fight. "

  (Hilary Evans, March 2016, quoted in Health as a Social Movement, NESTA, 2016.[8])

Notable aspects are highlighted in table 2 and an overview of the structure and content of the Dementia Fellowship Programme is appended (Appendix A).

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[8] NESTA. Health As A Social Movement. London: NESTA; 2016.

Table 2 - Notable aspects of the Dementia Fellowship Programme

Theme	Key learning activities	Design rationale
Residential modules	Included an evening session offering a different perspective on dementia, such as a screening of a film on music and dementia, a session with a theatre group, or a master class with an external speaker.	Breaking down barriers between professions. Building trust. Giving people space to reflect on and share their experiences of offering care. Creating time to have informal and creative conversations about change. Building relationships and networks. Expanding horizons. Offering the time to do/learn things that there usually was not time for in the working day.
Project work between modules	Cohort 1 and 2 participants were tasked with carrying out a coding exercise to review whether dementia registers captured all likely patients with the condition. Participants in cohorts 2 and 3 carried out local improvement projects, testing out the tools and approaches they were learning to introduce service change.	Grounded. Concrete. Attention to the real. Small changes ARE possible Putting new knowledge into real practice. Finding out pitfalls – coming back to reflect on how to solve unanticipated problems. Rebuilding resolve for change.
Networking conferences	Two cross-cohort conferences formed a key element of the programme, with a third planned for late 2017. Designed for sharing learning and strengthening professional networks within and across cohorts.	Connect the cohorts. Build geographical links. Showcase real change. Hear in depth from patients and their families about their experience. Hear from leading clinical experts.
NHS networks site	The programme team set up a shared NHS Networks site to facilitate the development of sustainable networks for change and improvement and to support engagement with wider NHS developments and learning. 54 Fellows are members.	Get used to looking things up on a leadership and change network where other service improvement work was posted – exposure to new learning.
Funding and location	The Dementia Fellowship Programme was fully funded, so Fellows were not charged to attend. In addition, funding was available for locum cover, where required. All modules took place in a centrally located hotel near Gatwick Airport.	Enable GPs and others who find it difficult to access stretching training to attend and fully participate without undue impact on their practices/services.

The learning from previous national programmes was crucial in shaping the design and learning intentions of the Dementia Fellowship Programme. A brief overview of the evidence relating to developing leadership capacity and capability in health setting is appended (Appendix B).

In particular, the design and approach of the Dementia Fellowship Programme drew on experience of the London Darzi Fellowship Programme, which had the specific intention of achieving a 'mind shift' in clinicians' capability to understand and lead change. BF and PG had both been part of Darzi programme leadership teams nationally, and the experience from leading these and other similar clinical leadership programmes was key to the development of the Dementia Fellowship. The evaluation of the Darzi Fellowship Programme, which was published by the Institute of Education in 2010, has provided a useful framework for this evaluation of the Dementia Fellowship[9], as the two programmes share an intentional similarity of purpose and design.

Introduction to the Evaluation

Aims and objectives

The overall aim of the evaluation was to understand the **value** and **impact** of the Dementia Fellowship training programme for the Dementia Fellows themselves, their practice and their wider sphere of influence. Cohorts 1, 2 and 3 were included in the evaluation.

A number of evaluation questions were to be addressed, relating to participants' experience, outcomes and learning for others. We were particularly keen to understand whether and how participants' learning had translated into improved practice and service offers for people with dementia. Sources of data were:

- Document review (e.g. programme details, participants' applications)
- Telephone interviews (Phase 1)
- Face-to-face interviews (Phase 2)
- Site visits (Phase 2/3)

Leadership and change frameworks for analysis

The 2010 Institute of Education evaluation of the NHS London Darzi Fellowship programme has provided us with a framework to analyse the personal leadership and change management data derived from phase 2 interviews and case studies (Figure 1).

The dimensions for the analysis of impact on individuals were:

- Self understanding and personal skills
- Organisation and system context of change
- Working with others
- Change management, service improvement and capacity building
- Beliefs and values
- Revised career aspirations

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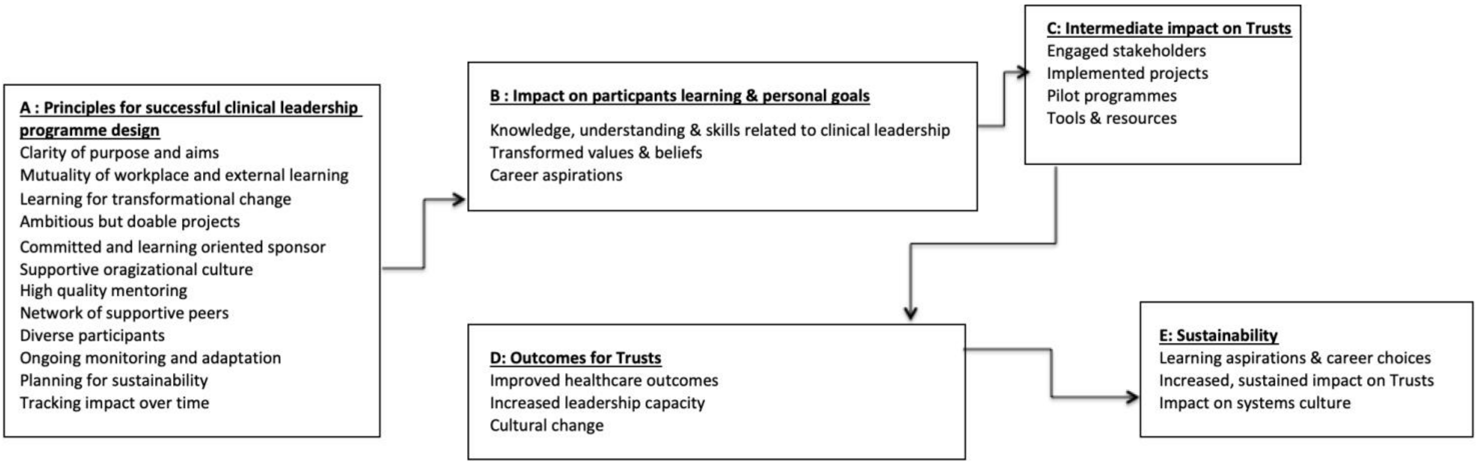
[9] Institute of Education (UK). Mind shift, an evaluation of the London 'Darzi' fellowships in clinical leadership programme. London: London Centre for Leadership in Learning; 2010.

Figure 1 - leadership learning framework (adapted by Jane Carrier and Dr Edana Minghella)



Evaluation constraints

The evaluation had a number of constraints that affected the methodology, the evaluation process and the findings:

- This was a *post hoc* evaluation – we could not empirically compare the knowledge and skills of Fellows pre and post the programme
- Engaging busy clinicians to the evaluation was difficult, not least because some of the interviews were scheduled at a time of extremely high demand on services
- Attributing service change to the Dementia Fellowship was not always possible and is never a simple linear cause and effect, as highlighted by a recent evidence review from the King's Fund, which reinforces the challenges of evaluating interventions of this kind[10]
- The evaluation did not include direct research with people living with dementia

In the context of these constraints, the evaluation team took a pragmatic approach, working with Fellows who were interested to contribute, and focusing on changes and impacts that Fellows made known to them or that the Dementia Fellowship team were aware of. This necessarily meant some self-selection and bias in terms of the findings.

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[10] The King's Fund. Leadership and leadership development in health care: the evidence base. London: The King's Fund; 2015.

A note on the use of quotes and vignettes

Direct quotes from interview transcripts and examples in the form of vignettes were used to illustrate findings. Criteria for the choice of quotes and vignettes were:

- Clearly expressed a view or experience
- Illustrative of the text
- Examples of common themes or strongly held opinions/ unusual examples
- Provide variation to illustrate, as a whole, the range of Fellows' views, experiences and initiatives

Appendix C provides more detail about the evaluation questions, methodology and data sources.

Section Two- The Dementia Fellows and their experience

Introduction to Section Two

Sections two and three present the findings of the evaluation. In this section, we provide a brief overview of the population of Dementia Fellows and our sample of interviewees. We also present findings from our interviews and document reviews about Dementia Fellows' aspirations and overall experiences of the Fellowship.

SUMMARY

- 75 people completed the first 3 cohorts of the Fellowship. The largest group were GPs (32, 43%), followed by nurses (25, 33%), hospital doctors (10, 13%), commissioners and others (8, 11%) made up the remaining disciplines
- 44 people out of an available 64 Fellows (68.8%) were interviewed for the evaluation
- Fellows in all cohorts and across all disciplines described the Fellowship in overwhelmingly positive terms
- Networking: in particular, learning from others, was regarded as a key strength, bringing together acute and primary care and enabling participants to understand each other's roles and to see across the whole pathway
- Fellows also appreciated how the course was structured (especially the residential element). They liked the focus on practical change in making a difference and the quality and composition of both the delivery team and external speakers – notably those who came with personal experience
- Where people were less satisfied, they most commonly mentioned that they found it difficult to implement the leadership and change management learning in their own organisations

Chapter 2: Overview of Participants and their experience of the Fellowship

This evaluation analyses the experience and impact of the Dementia Fellowship's first three cohorts, which were attended by 75 people:

- Cohort 1 – 21 participants
- Cohort 2 – 30 participants
- Cohort 3 – 24 participants

The biggest professional group of participants were GPs (n=32, 42.7%) with a sizeable proportion of nurses from both hospital and community settings (n=25, 33.4%). The ‘other group’ included allied health professionals and commissioners. Almost half of participants were based in Sussex (n= 35, 46.7%). See Appendix D for further details about the full population of participants.

Of the 75 participants, a number were ‘lost to follow up’ for a range of reasons: retirement, personal reasons and moving away (n=11), leaving 64 available for inclusion in the evaluation. Of these, a total of 44 Fellows were successfully interviewed, resulting in a 68.8% response rate. We interviewed half of the doctors (GPs and hospital doctors) on the Fellowship and almost three-quarters of the nurses.

Aspirations of Dementia Fellows

Our sample of Dementia Fellows had a range of aspirations on applying for the Fellowship. The key themes are presented in figure 2. In summary, Fellows wanted to learn more about dementia, to improve diagnosis and care, and the support to make change happen.

Figure 2 - Aspirations of Dementia Fellows

IMPROVED UNDERSTANDING OF DEMENTIA

- What's in place
- What's needed
- How to live well with dementia

BETTER CARE AND SERVICES

- What does good look like ?
- Improved diagnosis
- A greater role for primary care
- A holistic approach
- Improving commissioning

BETTER PATHWAYS AND INTEGRATED CARE

- Proactive approached and preventing admission
- Improving integration between primary and secondary care
- How to strenghten connections across the system

BECOMING A LEADER FOR CHANGE

- Support for the Dementia Fellowship incliding networking opportunities
- Building capactiy and ability to lead
- Moving from clinical skils to delivering local change

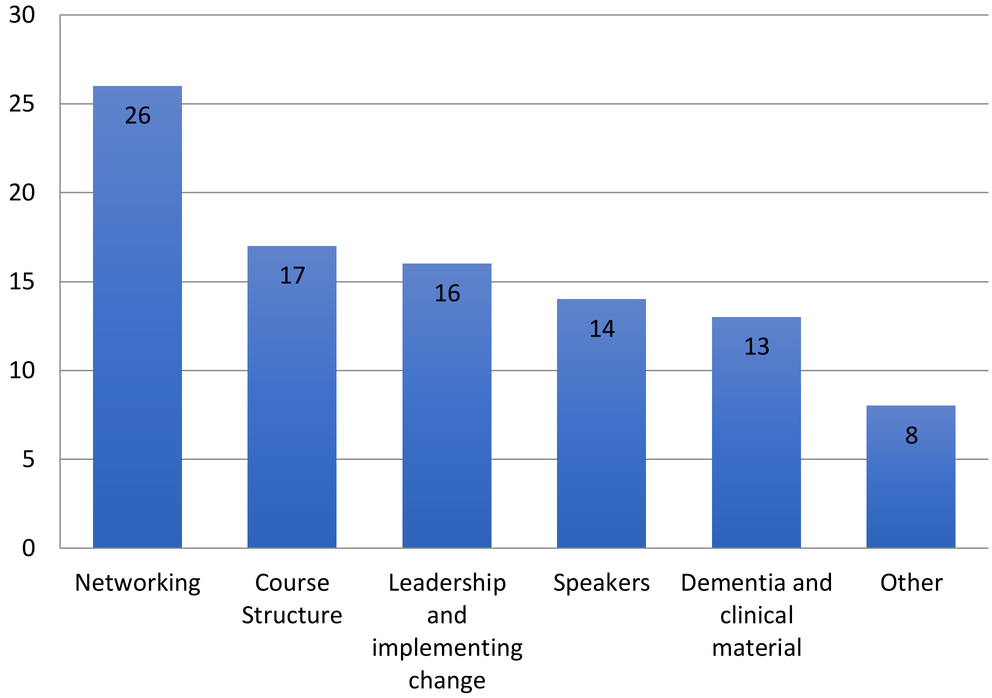
RAISING AWARENESS ABOUT DEMENTIA

- Improving knowledge and awareness among colleagues
- Shoring knowledge with the public

The evaluation interview data provided more complexity to these themes. For example, some Fellows who had longstanding experience in the world of dementia, either as dementia practitioners or as specialists, hoped to get *advanced* knowledge of dementia from the Fellowship; others had very little existing knowledge of dementia and therefore wanted an entry-level understanding. A third group had existing knowledge and wanted a refresher or to bring their knowledge up to date. These variations in aspirations had an impact on the experience of the Fellowship training for individuals, discussed in the next sections.

Overall experience of the Dementia Fellowship – what worked well?

Figure 3 - "What worked well?" – frequency



Fellows in all cohorts and across all disciplines were overwhelmingly positive about the experience of the Fellowship.

> *"It was fantastic, tiring and all-consuming, and I'd do it all again! Absolutely brilliant."* (Nurse)

Participants enjoyed all aspects of the Fellowship: the content, structure, delivery and the opportunity to learn alongside other disciplines.

Figure 3 shows the range of positive responses to the question "What worked well?" in order of frequency (i.e. the number of respondents who answered with a given response). Note: some respondents provided more than one answer to the question.

Networking

> *"The mix of primary and secondary care gave a real understanding of what connects us." (Nurse)*

> *"The things other people were doing were inspiring." (Nurse)*

By far the most frequent answer related to 'Networking' (26 respondents out of 44, 59%). Networking was regarded as a key strength, bringing together acute and primary care, enabling participants to understand each other's roles and to see across the whole pathway.

Looking in more detail, answers categorised as ‘networking’ referred to a variety of experiences that included the following:

- Hearing the perspectives of colleagues working in different parts of the system
- Making new contacts to build knowledge and learning
- Learning from others’ experiences in implementing change
- Sharing one’s own experience and roles
- A sense of solidarity: all in it together

Programme structure

> *“Having time away from the practice was key. It was a very good time to think about things, take stock, and think about doing it better. It’s easy to get caught up in fire fighting. It’s good to get your head up.” (GP)*

The second most common response to “What worked well?” was the “programme structure” (17 respondents out of 44, 39%). The structure was commonly described as “excellent”, the programme “well-organised” and the different elements “well-balanced.” Participants particularly valued the time away from clinical work, the blocks of time with gaps in between to process and reflect, and the residential elements.

Leadership and implementing change

> *“It gave us a toolkit to go away and lead improvements.” (Nurse)*

The content and quality of the Fellowship were well received and leadership and implementing change – including thinking about self-awareness and other interpersonal skills - were mentioned positively by 16 of the 44 Fellows (36%).

The focus on practical change and making a difference was regarded as very positive.

For some, learning about leadership skills and service redesign was new and timely. For example, one GP had just become a Partner and the leadership element enabled them to think for the first time about how to take on a clinical leader role effectively. Conversely, a number of people had undergone leadership training before, but found the Dementia Fellowship learning much clearer and more helpful than previous experiences.

> *“I really found the stuff on leadership and change management particularly useful. I’d done some before but the way it was delivered made more sense. It crystallised my knowledge.”* (GP1)

The quality of the speakers and facilitators

> *“Buz’s session was a bit like a bible for me when I went out to work with staff in care homes.” (Nurse)*

The speakers, their quality and their reputation, were all mentioned as positive aspects of the Dementia Fellowship by 14 of the 44 respondents (32%). Professor Banerjee was widely regarded as a ‘draw’ and his knowledge, experience and expertise were clear attractions, influencing applicants' decisions to apply for the Fellowship in the first place. At the same time, he was also valued as a speaker:

> *"Sube was absolutely fantastic – he's so grounded, he pitches it just right."* (Nurse)

Other speakers were also praised, especially those representing the perspective of carers and others living with dementia, which had a lasting impact:

> *" I still think of Buz whenever I see a patient [with dementia]."* (Dementia Fellow)

The overall balance of speakers, the 'delivery team', was also appreciated. One person summed this up:

> *"Breda's and Vikki's contributions, Pippa's wider strategic view, Sube's clinical expertise: the team's roles and contributions were complementary."* (Dementia Fellow)

Clinical content

> *"You think dementia is one of those scary things, but [the programme] gave you a new way to look at it." (Hospital doctor)*

The course content relating to dementia and clinical work was mentioned positively by 13 out of 44 respondents (30%) and particularly appealed to GPs and hospital doctors. There were three main categories of comments:

1. The coding exercise was especially valued by GPs, who incorporated the exercise into their routines and directly improved their diagnosis rates.

2. Learning new material or refreshing existing learning.

3. Providing a new way of looking at dementia that instilled confidence and also, that deviated from a purely medical model.

Other comments

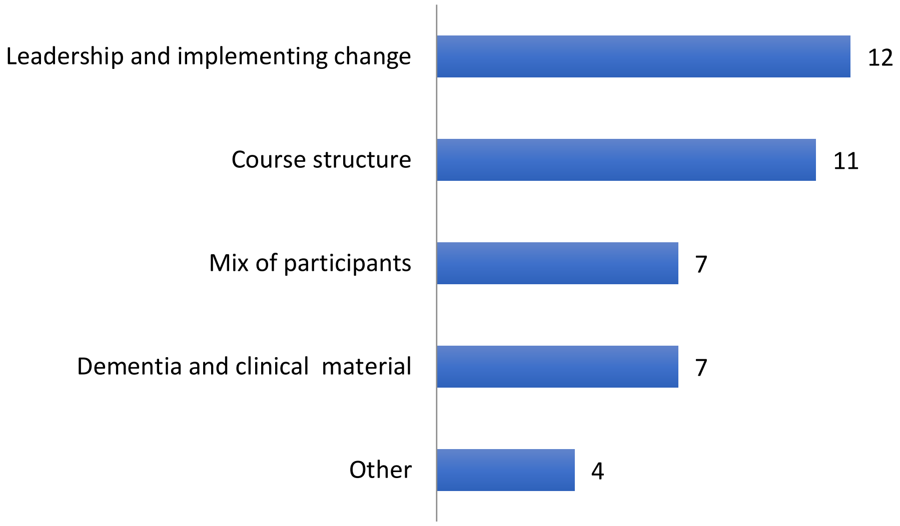
Other positive responses included the value of backfilling for GPs and the sense that all participants' opinions mattered, of being listened to. Backfill funding in particular was mentioned by several GPs as being absolutely essential to their being able to attend the course.

Overall experience of the Dementia Fellowship – what didn't work so well?

The overall experience of the Fellowship was extremely positive for nearly all participants; indeed, some Fellows, when asked what had not worked for them, had nothing to say. Those who did have a response were mainly concerned about the programme structure (primarily, the intensity of it and how tiring it was). There was also some frustration about how to apply the learning in practice – how to make change happen – especially when the Fellow felt they were in an isolated role (a lone hospital doctor, for example) or a role with little power to influence (community dementia nurse).

Figure 4 shows the range of responses to the question "What didn't work so well?" in order of frequency (i.e. the number of respondents who answered with a given response). Note: some respondents provided more than one answer to the question.

Figure 4 - "What didn't work so well?" - Frequency



Leadership and implementing change

> *"The leadership element was interesting but I'm a sole practitioner... there's not a lot I can do with it at the moment." (Nurse)*

Twelve of the 44 respondents (27%) expressed some misgivings about the leadership and change management elements of the programme, with the majority of this group (8 out of the 12) expressing disappointment about the extent to which they were able to implement change in practice. Even when they enjoyed the content, there was a sense of frustration about what was practically possible in the context of financial pressures and a lack of a strong strategic focus on dementia in their clinical areas, or because they felt that their roles did not allow them to implement any leadership or change management learning.

> *"One negative thing: the course was really inspiring, I made plans, but when I tried to implement change, I contacted the dementia lead -- nothing really transpired. Nice to have goals but unrealistic." (Dementia Fellow)*

Programme structure

> *"The days were very long, and it was sometimes hard to stay engaged for the whole day." (Nurse)*

Eleven of the 44 respondents (25%) talked about the programme structure in response to the question "What didn't work so well?". Even those who liked the structure found the Fellowship very intense and tiring, and the days long, exacerbated in some cases, by the travelling time involved.

The intensity of the programme affected some people's ability to enjoy and engage with the content.

Two respondents expressed strong views that some evening sessions explored particularly sensitive areas and that they were left with difficult feelings:

> *"Putting difficult emotional things at the end of the day --- anxiety, anger, should have been anticipated."* (Dementia Fellow)

Mix of participants

A few (7 out of 44 respondents, 16%) were dissatisfied with the mix of participants on the programme. Some (non-doctors) felt the Fellowship was aimed at GPs, with one person saying they felt 'misled' that it was relevant to their role. There was also a concern expressed that a key part of the system – that of care homes – was not represented.

Dementia and clinical material

There were two main concerns expressed about the dementia and clinical content (by 7 out of 44 respondents, 16%):

- Some felt that the level of dementia knowledge was too basic, especially for those who were already dementia specialists
  "We went over old ground. It was nice to have a refresh but it was just not as in-depth as I expected. It didn't enhance my knowledge." (Dementia Specialist Nurse)

- Others felt that the clinical coding exercise was not relevant to their practice.
  "Some of us already are already specialists, passionate. We didn't need the stuff about coding and there was too much emphasis on diagnosis… Just a diagnosis isn't good enough. It needs more than that." (GP, cohort 1)

Other

The most common other concern (6 of the 7) was a wish for on-going support, including support to maintain networks with each other, and support to access other local and national networks and learning opportunities. This was a significant finding because networking while on the programme had been such a strong positive experience for participants. This point is discussed further in section four.

Section Three- The impact of the Fellowship for individuals, services and the wider care system

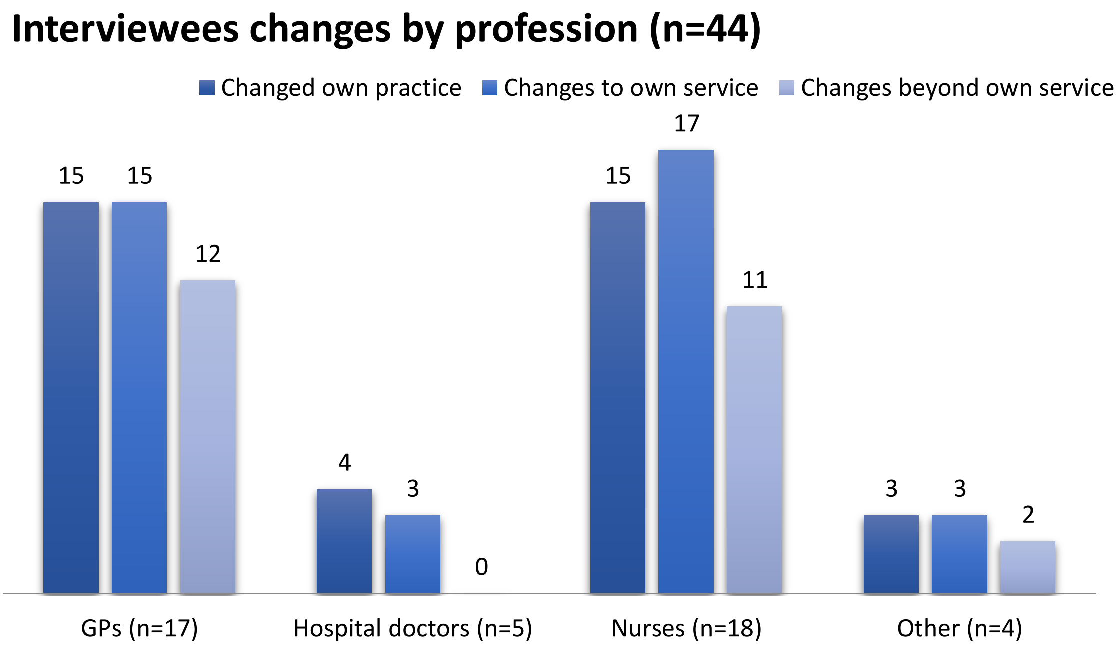
Introduction to Section Three

This section presents the evidence that the evaluation found on the impact that the Dementia Fellowship had on Fellows, on the services in which they worked, and on the wider care system in their area.

Through the interviews and analysis of changes the Fellows experienced and initiated, we found that there was an impact on nearly everyone at the levels highlighted in the evaluation of the Darzi Fellowship programme in terms of:

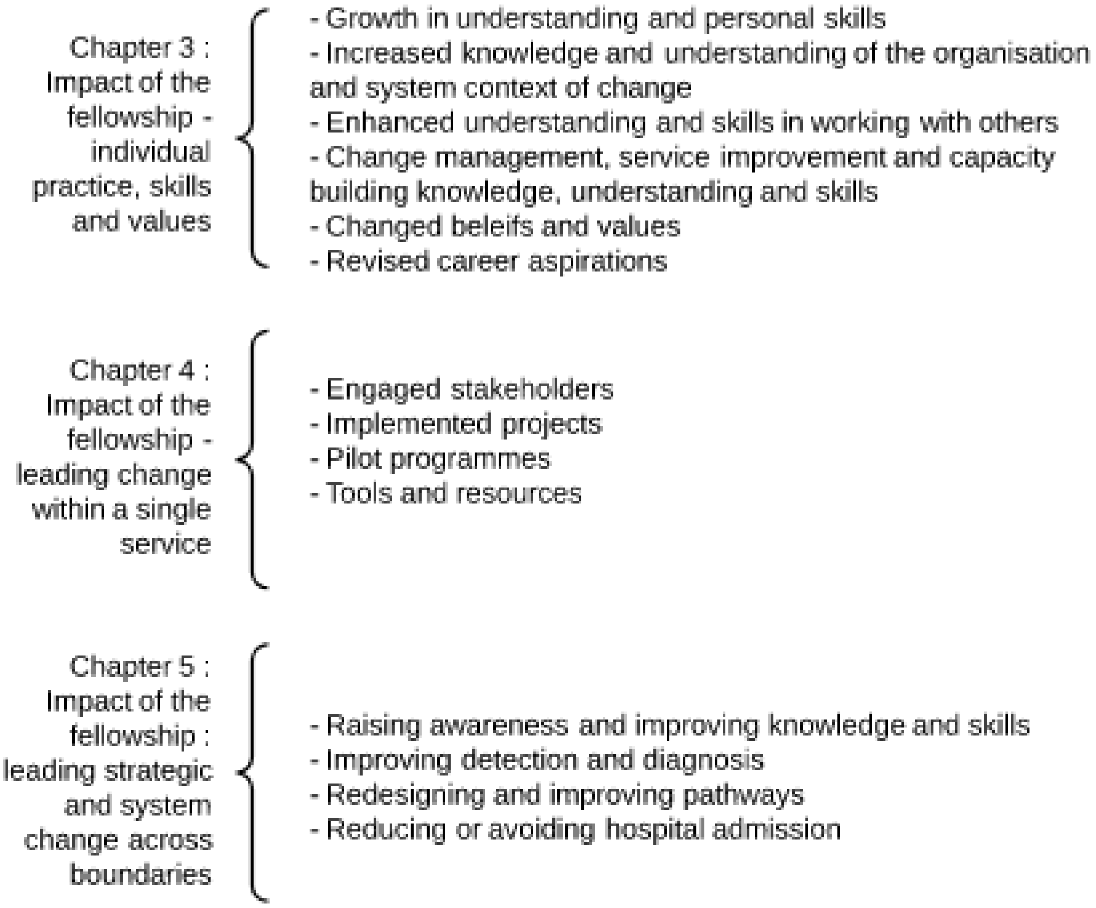
- Their own personal development (including clinical and interpersonal skills)
- Changes that they made within their own service
- Wider system or strategic changes beyond their own clinical practice (Figure 5)

Figure 5 – Changes by profession



Findings presented at each level are structured around a number of impact areas in the next three chapters. For individual and service change, these are derived from the Institute of Education evaluation of the NHS London Darzi Fellowship. When looking at system change, we have developed a framework derived from the data gathered from Fellows (Figure 6).

Figure 6 - Impact framework by chapter



Chapter 3 : Impact of the fellowship - individual practice, skills and values

- Growth in understanding and personal skills
- Increased knowledge and understanding of the organisation and system context of change
- Enhanced understanding and skills in working with others
- Change management, service improvement and capacity building knowledge, understanding and skills
- Changed beleifs and values
- Revised career aspirations

Chapter 4 : Impact of the fellowship - leading change within a single service

- Engaged stakeholders
- Implemented projects
- Pilot programmes
- Tools and resources

Chapter 5 : Impact of the fellowship : leading strategic and system change across boundaries

- Raising awareness and improving knowledge and skills
- Improving detection and diagnosis
- Redesigning and improving pathways
- Reducing or avoiding hospital admission

Chapter 3: What was the impact of the Dementia Fellowship on participants as individuals?

SUMMARY

- Most Fellows (37, 84%) reported improved self-development and professional practice through completing the Fellowship
- The programme had a profound impact on Fellows' perceptions of people with dementia, and shifted many of them towards a much more person-centred approach. Hearing from people with lived experience and experiential learning exercises were key to this change
- Fellows also reported a greater awareness and understanding of the role and needs of carers
- Fellows reported increased confidence. Nurses in particular reported a strengthened sense of self worth and GPs felt more confident assessing people with dementia
- Organisational understanding improved, with Fellows making better use of organisational resources and showing increased understanding of how best to achieve change in local context
- Relationship, persuading and influencing skills improved

This chapter is structured using the six dimensions of personal and professional change developed by the Institute of Education in their evaluation of the London Darzi Fellowship.

Impact area 1 - Growth in self-understanding and personal skills

> *"It empowered me as a GP…gave me a holistic view, not a medical model."* (GP)
>
> *"The DF helps you think about how you perceive yourself. You suddenly realise – what I have to say is important."* (Nurse)

Almost all the Fellows who contributed to the evaluation highlighted increased confidence in their ability as an important impact of the Dementia Fellowship Programme, although this was expressed in slightly different ways for different groups. Some Fellows, notably GPs, had relatively little knowledge about dementia before starting the programme, but acquired sufficient clinical knowledge and confidence to manage the care of people with dementia within their practice:

> *"…giving us agency and ability."* (GP)

A number of Fellows referred to specific changes in their clinical practice. Several mentioned spending more time with people with dementia, such as this accident and emergency doctor:

> *"I now spend an extra few minutes with patients (with dementia). I'm more aware of giving people extra time."* (Hospital doctor)

Some of the more experienced Fellows already had a high level of clinical skill, but for many, the programme reinforced and refreshed their existing knowledge as well as strengthening their sense of themselves as competent and well-informed practitioners. Several nurses spoke about the role the Fellowship had played in boosting their personal and professional confidence, and in enabling them to take on challenges that they would not previously have contemplated. The support of peers on the programme, as well as the team, strengthened self-belief, and helped Fellows to take action to improve services in their organisations.

The Dementia Fellowship also prompted some Fellows who were relatively new to dementia to become deeply engaged with the issue.

> *"I've become evangelical about dementia."* (GP/Commissioner)

For others, who were already working in specialist roles, the programme re-awakened their enthusiasm and re-energised their commitment:

> *"I came away rejuvenated. This was apparent in my own teaching and training."* (Nurse)

Some Fellows described how the programme had prompted them to reflect on their working style, and realise that a reactive approach was distracting them from their goals. One or two noted that they had improved their self-organisation and their ability to plan and prioritise.

Several Fellows mentioned the importance of their own experiences with people with dementia, either family members or friends. In some cases, this personal legacy had influenced their decision to attend the programme and underpinned their commitment to the issue.

> *"My father had vascular dementia. I wish there had been more to support him. It spurred me on*." (Paramedic)
>
> *"My passion came from the Dementia Fellowship. Then a few months later, my father was diagnosed with dementia."* (GP)

The Dementia Fellowship therefore increased clinical and personal confidence, and changed practice, for example in allowing more time to work with people with dementia. It refreshed the existing clinical knowledge of some, and strengthened self-organisation for others, while enabling one or two to connect deeply with an issue that had affected them personally.

Impact area 2 - Increased knowledge and understanding of the organisational context of change

> *"As a GP it showed me I don't have to do everything."* (GP/Commissioner)

Fellows reported a range of ways in which their organisational understanding had improved since attending the programme, such as making better use of resources within their organisations, and using organisational levers to achieve change.

For some GPs, the Dementia Fellowship demonstrated that making changes does not inevitably mean more work for individual GPs. Other professionals and organisations, within the practice and in the community have a key contribution to make. Reviews of the evidence on developing the capacity of doctors as leaders for change highlight the importance of this learning point[11].

Several GPs spoke of realising that new work can be embedded systematically at a practice level, by involving practice nurses or the administration team. One Fellow, for example, saw that, even as a busy GP, they could still help to bring about small changes for people with dementia by passing on knowledge and setting up new ways of doing things. Another successfully built the review of the dementia register into the practice's work programme, as described in box 1 below.

"Without the Fellowship I wouldn't have had the time to think deeply about leadership."

For this Fellow, a new GP partner, the Dementia Fellowship came at the right moment, as it enabled them to reflect on their new leadership role, how to influence colleagues and bring about change within the practice. The experience of carrying out the review of the dementia register highlighted the importance of embedding developments into the work of the practice, rather than attempting to manage it alone:

"Learning about leadership (made me realise) you don't just sit in a silo – you get someone trained up, get them looking at it regularly. It runs at a practice level, not at the level of a single clinician."

Box 1 Example – Embedding change in the work of a practice

Several nurses described the ways in which the Fellowship had encouraged them to think more analytically, increasing the sophistication of their way of working to influence change within their organisation. A lead nurse in an acute trust, for example, highlighted that attending the Fellowship had supported the difficult transition from practitioner to strategic leader:

> *"I love the clinical work, but I realised I have to step away from that. The service needs to be here when I've retired. It needs to be embedded."* (Nurse)

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[11] Bohmer R. The Instrumental Value of Medical Leadership: Engaging Doctors In Improving Services. London: The King's Fund; 2012.

Since attending the programme, this GP has developed a more strategic approach to their role. Initially they approached the role as a practitioner, but the Fellowship helped make the transition towards a broader perspective, working through others to achieve change. They now view developing strong networks across the trust as key, and are more skilled at using the hierarchy when necessary.

Another lead nurse 2 described how they made use of organisational systems in a more considered way since attending the Dementia Fellowship (Box 2).

One Fellow is the lead dementia nurse for an acute trust. Through the Dementia Fellowship, they became more thoughtful and analytical about their role as a leader and influencer. More attention is now given to using internal levers to achieve goals, for example in securing increased resources for dementia. Arguments are marshalled carefully, and they consider which approach to deploy in which circumstances. He/she also picks battles in a strategic way:

> *"Recognising lost causes and understanding the bigger picture."*

This Fellow is now leading the refresh of the trust's dementia strategy, and is taking a much more proactive approach than for the first strategy they led. They are now much more confident in occupying a leadership role, and clear about what needs to be done. They are also making connections with other areas in the strategy, for example falls and end of life care, demonstrating an increased awareness of the wider organisational context of change.

Box 2 Example – Using internal levers

Impact area 3 - Enhanced understanding and skills in working with others

> *"It was my first taste of taking ownership of something in the practice...having time to explore it and negotiate…getting people motivated, encouraging, cajoling."* (GP)

As noted above, Fellows evidenced an increased understanding of their place within their organisation, the resources they could draw upon, and how best to achieve change in their local context. This relies on skills in working with others at all levels of the organisation, as well as with external partners and other stakeholders.

Many Fellows referred to the importance of the multidisciplinary nature of the Dementia Fellowship in breaking down barriers between professional groups. For example, a lead nurse, highlighted that the Dementia Fellowship had improved relationships with doctors. During the programme they had worked alongside doctors as peers and equals, and had spent time getting to know and understand them as individuals. As a result, they now felt more confident and empowered in strategic discussions:

> *"I can hold my own because I did it on the Dementia Fellowship."* (Nurse)

Many Fellows spoke about building relationships with other services or organisations, which in some cases led to new connections and developments. One GP mentioned referring a man with dementia to a local Men in Sheds group, while a Fellow who works in a hospice made new connections with the Alzheimer's Society, which led to a range of partnership initiatives (described later Box 11 – Improving access to hospice care for people with dementia).

After attending the programme, many Fellows started acting as a resource for colleagues, either formally or informally, and their enhanced knowledge and skills were recognised.

The multidisciplinary, multiservice design of the programme meant that Fellows built a broad picture of dementia care across Kent, Surrey and Sussex, which they were able to use in making a case for change within their own organisation:

> *"It's powerful to say 'They're doing this in Guildford – why aren't we doing it here?' "* (Hospital doctor)

Impact area 4 - Change management, service improvement and capacity building knowledge, understanding and skills

> *"I influence change through my juniors …"* (Hospital doctor)

The evaluation found a few examples where Fellows had used improvement methodologies formally, and a small number of Fellows did report that these approaches continued to inform their work. For example, a doctor in emergency care, still draws on the change and improvement tools learned on the programme in a new, more senior role. Using the leadership skills acquired with the junior doctors this Fellow passes on the tools and techniques to them.

A theatre nurse systematically considered an approach to introducing a service change to the recovery service in an acute hospital. While service improvements had previously been made, the Fellowship provided tools to plan a successful influencing strategy, by thinking carefully about how best to bring people on side, and how best to approach them:

> "*People don't like change. You have to court them.* " (Theatre Nurse)

Impact area 5 - Changed beliefs and values

> *"How do I make sure that people's voices are heard? The Dementia Fellowship gets you thinking more deeply about what person-centred care really is."* (Nurse)

> *"It made me think about the patient and carer's perspective. Once you start thinking about that, you apply it to other areas of your work."* (Nurse)

A change in beliefs and values can act as a fundamental lever for change, and we found strong evidence that the Dementia Fellowship had an enormous impact in this area.

Many Fellows highlighted the sessions on person-centred approaches as particularly memorable and important for them, resulting in a profound impact on Fellows' perceptions of people with dementia, and shifting them towards a much more person-centred approach. For some GPs, this shift was also benefiting other patients.

An Accident and Emergency doctor, now spends time building a rounded picture of the person with dementia by speaking with families or care homes to understand better what is usual for that person, and not admitting as the default response. The following story illustrates the shift in approach.

An older person with dementia was admitted to Accident and Emergency after being found wandering in a seaside hotel during the night. Accident and Emergency staff were about to admit, commenting *'She **has** to be admitted – she's confused!'*.

When the family arrived, this doctor spoke with them, established that this was not unusual behaviour for the person with dementia, and discharged them back to the hotel, where family had taken them for a holiday and to relive happy memories from the past.

Box 3 Example – Person-centred approaches in Accident and Emergency

Fellows spoke about seeing the person behind the diagnosis for the first time:

> *"Not just one of a list of co-morbidities."* (GP)

This change in attitude was also reflected in, for example, the involvement of people with dementia and their carers in delivering training to NHS staff and in strategic groups:

> *"Having carers in a group means it's not just a bunch of health professionals saying 'It should be like this.' "* (Doctor)

> *"As a carer I feel valued here."* (Dementia Fellow)

Indeed, the Dementia Fellowship fundamentally changed views about the place of carers, with many of the Fellows introducing developments focused on carers, some of which are described in the following chapter.

Impact area 6 - Career aspirations

> *"[I'm now] involved in service development, I have a new [much more senior] role and I'm about to lead my first research project. The Dementia Fellowship was pivotal in all this."* (Nurse)

> *"I'm now the dementia lead for my practice. I wouldn't have taken this on without the Dementia Fellowship. I would have shied away from this."* (GP)

As noted earlier, the Dementia Fellowship increased the confidence of many Fellows, in line with one of the key intended outcomes of the programme. For a small number, the programme acted as a springboard for career development. One Fellow was appointed to a more senior role, another found the Fellowship enhanced job applications, while others took on leadership roles related to dementia within their organisations. This was not, however, an area that the evaluation explored in detail.

SUMMARY

- 38 Fellows (86% of those interviewed) introduced changes within their own services, in every setting including primary care, hospitals and a hospice
- Key changes in primary care – often linked – were improvements to dementia coding and increased diagnosis rates, training, and dementia friendly practice
- This contributed to a tangible measurable difference in Kent, Surrey and Sussex. For example, dementia diagnosis rates increased from 43% to 68% in one CCG area
- Many initiatives featured training or skilling up colleagues. Hospital and community nurses notably made changes through training, often incorporating sessions they found useful from the Fellowship training into their own courses

Chapter 4: What was the impact of the Dementia Fellowship Programme on – leading change within a service?

This chapter is structured around the four impact areas included in the evaluation of the Darzi Fellowship that indicate that service change is taking place:

- Engaged stakeholders
- Implemented projects
- Pilot programmes
- Tools and resources

Impact area 1 - Engaged stakeholders

Many initiatives introduced by Fellows aimed to skill up colleagues and sometimes to change attitudes of local people to dementia through training and development.

All the lead nurse Fellows had responsibility for the design and delivery of dementia training to staff across their trust. They commented that the Dementia Fellowship Programme had fundamentally changed their approach to training, both in terms of content, and also approach, with a much stronger emphasis on person-centred models, and on the experiences and feelings of people with dementia. Many of the Fellows who had a training role spoke about using some of the content and exercises from the programme within their own training:

> *"Using videos and exercises from the course within my own teaching with a focus now on **how it feels** to have dementia."* (Nurse)

The lead nurses are able to influence the care delivered to many people with dementia through their corporate training and development role. For example, one community trust redesigned and re-launched its dementia training programme to reflect the Fellow's learning from the Dementia Fellowship and 657 staff attended. The new programme brought in communication with people with dementia, the involvement of carers, and people with dementia and carers had a delivery role.

> *"It's about empowering staff to care well."* (Nurse)

Following the Fellowship, participants often reviewed and extended the scope of training programmes to include all the groups who might come into contact with people with dementia, such as porters and administrative staff. One Fellow described delivering a training programme to the trust's executive team alongside other staff, which sent out a powerful message about the importance of the issue:

> *"It was a positive step, as they did it with 'the troops'. I made them cry!" (*Nurse)

One Fellow*,* whose trajectory through the programme and the impact it had is described later in a case study, used **Alive Inside**[12], a film on the use of music with people with dementia, as the basis of a training programme. Working alongside contacts made through the Fellowship, the nurse worked with a local filmmaker to set up a series of screenings of the film, which were open both to staff and members of the public. Extending the screenings to the community was linked to an increasing focus on person-centred approaches that was gained through the programme. The impact went beyond NHS staff to raise dementia awareness in the community. Fifteen (15) screenings have taken place to date [May 2017], with more planned.

> *"The reach was far beyond anything I'd hoped to achieve."* (Nurse)

Impact area 2 - Implemented projects

This section describes service development projects and initiatives that Dementia Fellows carried out in their own organisations. It does not seek to capture every initiative, but highlights the main types of development, as well as those, which are unusual or particularly innovative. The developments are grouped according to the setting in which they occur. (The next section addresses developments that operate across organisational boundaries to improve pathways or aim to achieve change at a system level.)

Primary care developments

Developments within primary care settings fall within three broad groups:

- Improving the identification of people with dementia within the practice population
- Making primary care more accessible to people with dementia and their carers
- Increasing the range of services available to people with dementia in the practice

This section considers each of these three groups, below.

Improving the identification of people with dementia

The first two Dementia Fellowship cohorts were targeted primarily at primary care professionals. Both groups were tasked with carrying out an exercise in their own organisation to improve the accuracy of coding, in order to identify people with dementia who had not yet been included on the practice dementia register.

A presentation to the Dementia Fellowship's 2015 conference set out the impact of the coding exercise carried out by cohorts 1 and 2. Thirty-three (33) practices were involved in the exercise.

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[12] Rossato-Bennett M. Alive Inside [DVD]. USA: Projector Media; 2014.

The dementia register increased by 13.4% as a result of the Fellows' efforts, which equates to identifying 355 additional people with dementia in Kent, Surrey and Sussex.

> *"I sold the idea of a few relevant READ codes to my CCG and sold that to my colleagues too, so that we can do better with our coding. Our prevalence rates improved from 44%-67% and we came top in county."* (GP)

Improving the accuracy of dementia registers is a national priority, as it ensures that people living with dementia and their carers have access to the care and support they need. The coding exercise was also valuable in raising the profile of dementia in practices that did not previously acknowledge the scale of the issue, as described in the following example (Box 4).

A lead GP initiated an audit of case notes during the Dementia Fellowship Programme in August 2014, which was repeated in 2016. An additional 37 people with dementia were identified in the practice population as a result of these two audits. This increased the number of people with dementia on the practice dementia register to 54% of the predicted dementia prevalence. Although this falls short of the national expectation of 66%, it represents an increase of 8%, and brings the practice in line with the Clinical Commissioning Groups (CCG) average, according to comparison with national NHS recorded dementia diagnoses 2014/15.

This work by the lead GP for dementia in the practice, alongside the coding exercise, has challenged and influenced the views of colleagues and the culture of the practice. Previously the general view was that dementia was not a major issue for the practice's patients (who are predominantly fairly affluent and healthy).

> *"This was a big change – it showed colleagues there were people not picked up, and struggling. "*

The GP's priority now is to continue focusing on the underlying reasons for the low percentage of people who are identified within the practice population.

Box 4 Example – Reviewing the dementia register to challenge perceptions

Making primary care more accessible

Following the Dementia Fellowship, almost all GPs and other primary care professionals had introduced developments to raise awareness of dementia among practice staff and to improve the experience of people with dementia and their carers. These developments included skilling up staff, designating leads for dementia in the practice, improving the availability of information, and introducing environmental improvements.

Many GPs had ensured that all practice staff, including administrative, reception and clinical staff, were trained to deal well with people with dementia. External agencies, such as the Alzheimer's Society, sometimes delivered practice training, and sometimes the GP themselves took the lead, often using approaches and materials drawn from the Dementia Fellowship. In some practices, all staff became dementia friends, an Alzheimer's Society scheme.

As noted earlier, many GPs realised during the programme that providing a better service to people with dementia did not inevitably mean a significant increase in their own workload.

Instead, they could lead and work with others to deliver the changes that were necessary. Several GPs spoke about nominating a nurse, care assistant or administrator as dementia lead for the practice, working under their supervision (Box 5).

A lead GP for dementia worked with colleagues to make the practice much more dementia aware, for example by training staff, displaying materials on dementia, and introducing dementia friends. As a result of the programme, appointed two healthcare assistants to lead on dementia in the practice. The Fellow supported and trained them. Their role includes liaising with nursing homes and signposting people with dementia to local services.

Box 5 Example - A dementia aware practice

Some practices introduced process improvements, such as fast-track access to a GP, while others increased the availability of information on dementia, or introduced environmental changes to make the practice more dementia aware. While Fellows did not articulate a direct link between their improvements and the programme content, several highlighted the value of the content on service models. Further, the increased awareness of person-centred approaches, and seeing services through the eyes of people with dementia, highlighted earlier, are also likely to have influenced Fellows' actions in this area.

Increasing the range of services

In addition to gaining confidence in the treatment and management of dementia, some Fellows extended the range of additional support that people with dementia and their carers could access within the practice. In some cases, this involved opening up existing services to people with dementia, in others, it meant setting up a new service within the practice. The examples below (Boxes 6 and 7) evidence a broader and more holistic approach to supporting people with dementia, as well as their carers, with a focus on early intervention and supporting wellbeing. This connects back to earlier points about changed perceptions of people with dementia and their carers, and seeing the person behind the diagnosis.

After attending the Dementia Fellowship, a GP, volunteered to become dementia lead in their practice. They had valued the opportunities offered by the Fellowship to work with peers to think creatively about what might work locally, and had also learned more about the contribution of the third sector. They had been active in bringing new services into the surgery for people with dementia and their carers. A monthly dementia café is run from the practice by the patient participation group, supported by the Alzheimer's Society; patients with dementia and their carers can attend for support and advice from the practice dementia adviser. Care Quality Commission highlighted this initiative as an area of outstanding practice in their 2016 inspection report.

Box 6 Example – A dementia café in primary care

A GP partner, was dementia lead in the practice, and later volunteered to become lead on proactive care, as this would also benefit people with dementia:

"*It grew out of thinking about leadership, which led to (my) making connections.*"

The role involved developing a relationship with the Proactive Care Team, a multidisciplinary community team that aims to provide flexible health and social care support to help people with long term conditions continue living well at home. Most practices had limited contact with the team, who received many of their referrals from the acute sector. However, the practice decided to prioritise people with dementia and their carers, who were then referred to the team for on-going support. All now have a key worker and plans for emergency respite are in place. People with dementia in this rural area are therefore now able to draw on long-term support that was not previously available to them. As a new GP partner, the Fellowship was timely for this doctor. The leadership content sparked an interest in learning more about their preferred style, which was described as "*…collaborative and democratic*".

Box 7 Example – Supporting people with dementia to live well at home

Acute care developments

It was striking that some of the lead nurses were able to achieve considerable service change and improvement in acute care. Their strategic, trust-wide role required them to lead activity on dementia across the organisation and the Fellowship enabled them to develop their strategic and influencing skills, equipping them to rise to this challenge.

The Dementia Fellowship emphasised the critical role of carers. As a result, several lead nurses in acute settings focused on improving carer experiences by introducing greater flexibility or increasing and broadening carer support (Box 8). A lead nurse from cohort 3, for example, introduced a carer's passport across the organisation, which aimed to make explicit the level of contact carers want to have with the person with dementia while they are in hospital. This aimed to change culture and improve consistency and has now been expanded to include carers of all patients.

This lead nurse from an acute trust who joined cohort 1, chose a Dementia Fellowship improvement project to increase the trust's response to the carers of people with dementia. As planned, they carried out an audit in 2014. This was repeated in 2016, and demonstrated significant improvements in the past two years. The first audit highlighted weak links with local carers organisations. In response, the trust offered two local groups a hospital base, sharing space with the social services team. Negotiating the move required "*lots of cajoling and brokerage"*, highlighting skills in working with others. The presence of the two organisations in the hospital setting means that they are now more visible and are well used by carers across the trust. The Fellow feels that the leadership elements of the programme helped them to step up and shape services within the trust. After they found some of the sessions difficult at the time, the programme has helped them to be more conscious of their own behaviour and how best to achieve change.

Box 8 Example – Improving the experience of carers of people with dementia

One Fellow had a central role in introducing dementia-friendly environments and practice across all the older people's wards in an acute hospital, starting with a pilot on their own ward. This included introducing design features, such as colour coding of different zones, setting up relatives' rooms for carers, and changing policy to encourage visits outside usual visiting hours, including at mealtimes. Initial evidence showed a positive impact, including reduced use of sedatives, as patients were calmer and less stressed by the hospital environment and regime.

There were several notable examples of Fellows in general roles in acute trusts, such as accident and emergency doctors, or nurses in non-specialist roles, overcoming organisational barriers to achieving change, as demonstrated in the example below (Box 9).

"I can confidently say that I improved the care of dementia patients"

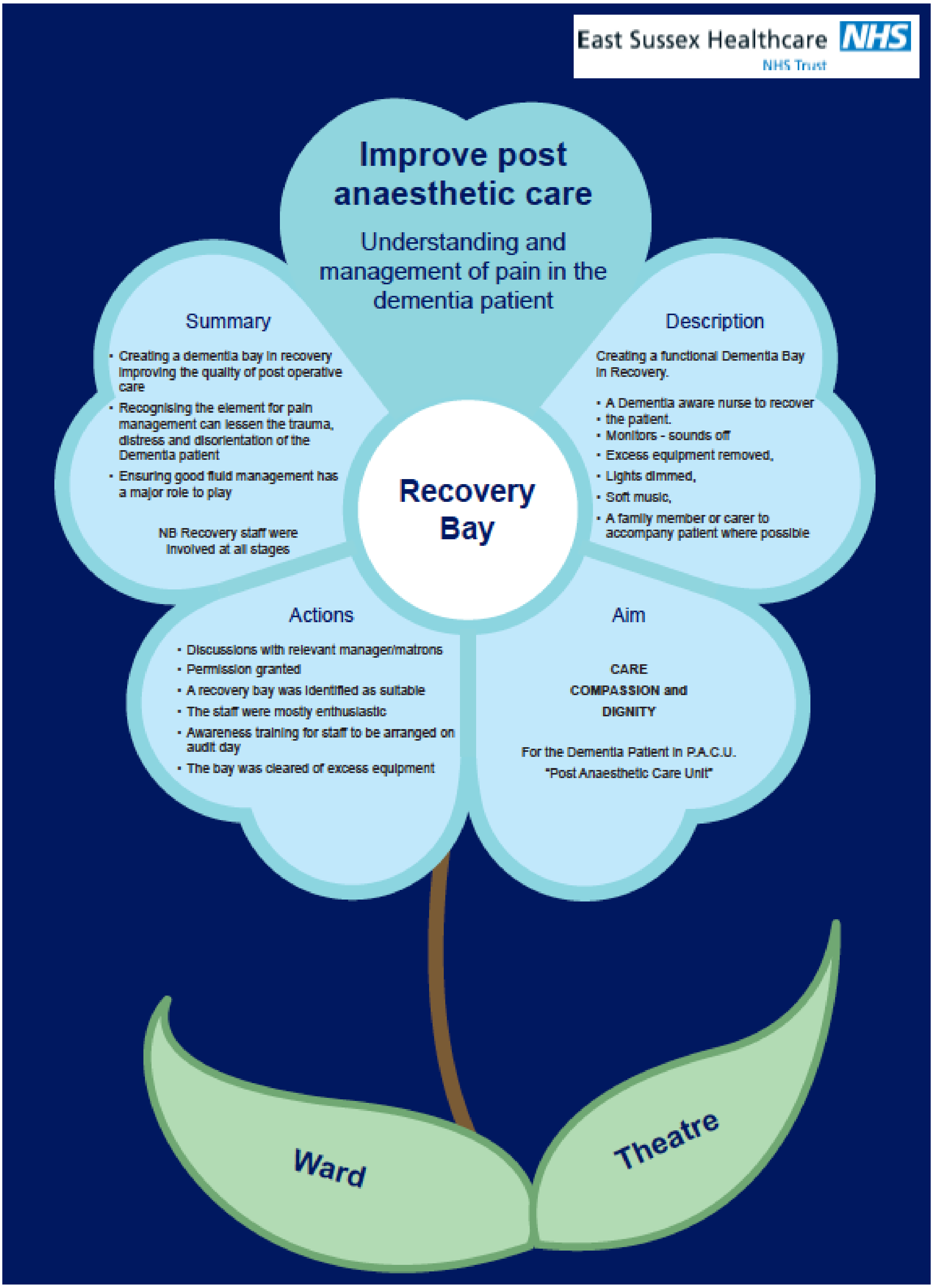
A theatre recovery nurse chose a Dementia Fellowship improvement project that introduced a dedicated recovery bay for people with dementia who had undergone surgery. They were especially inspired by the elements on person-centred approaches, and also the discussions with other Fellows on how to improve care.

The Fellow mapped out the project using a graphic in the form of a flower (Illustration 1), as they wanted to avoid "*a boring flow chart".* There was already a paediatric bay in place, so they thought the idea should be adapted for people with dementia. Although they had previous experience of managing a change programme, they drew on the leadership and change elements of the programme in thinking about who needed to be influenced in order to introduce the recovery bay. One bay was being used for storage, so they proposed that this should be used. Excess equipment was removed, the lighting turned down slightly, beeping tones of monitors turned off, a chair added for a carer, and soft music introduced. The Fellow also delivered an audit session for between 40 and 50 relevant staff. They had never done anything like this before. The graphic was produced as a large poster (with help from the trust's art department), which was put up shortly after the end of the programme.

Now with a new employer, a private hospital chain with 40 hospitals, this approach was adopted: the poster; and the recovery bay approach. The Fellow has visited hospitals in the chain to train them on the approach. The recovery bay is still in place and used in the original National Health Service (NHS) setting. The Care Quality Commission have commended this work, and Professor Alistair Burns, the National Clinical director for Dementia, has described the development as '*wonderful*', saying it should be rolled out across the NHS.

Box 9 Example – A dementia recovery bay

Illustration 1 - Improving post-anaesthetic improvement project graphic



East Sussex Healthcare NHS
NHS Trust

Improve post anaesthetic care

Understanding and management of pain in the dementia patient

Summary

- Creating a dementia bay in recovery improving the quality of post operative care
- Recognising the element for pain management can lessen the trauma, distress and disorientation of the Dementia patient
- Ensuring good fluid management has a major role to play

NB Recovery staff were involved at all stages

Description

Creating a functional Dementia Bay in Recovery.

- A Dementia aware nurse to recover
- the patient.
- Monitors - sounds off
- Excess equipment removed,
- Lights dimmed,
- Soft music,
- A family member or carer to accompany patient where possible

Recovery Bay

Actions

- Discussions with relevant manager/matrons
- Permission granted
- A recovery bay was identified as suitable
- The staff were mostly enthusiastic
- Awareness training for staff to be arranged on audit day
- The bay was cleared of excess equipment

Aim

CARE
COMPASSION and
DIGNITY

For the Dementia Patient in P.A.C.U.
"Post Anaesthetic Care Unit"

Smoothing the pathway

The evaluation also identified a group of developments aiming to smooth the pathway between the acute hospital and the community, either at admission or discharge. Fellows mentioned the Fellowship's emphasis on putting the person with dementia at the centre of care pathways as an important influence. One Fellow has worked with ambulance crews to improve the experience of an Accident and Emergency department (A&E) admission for people with dementia. This included introducing the **This Is Me**[13] document, and encouraging a carer or someone who knows the patient to attend with them. Another Fellow aimed to improve the interface between residential and nursing homes and the ambulatory care unit (Box 10).

One Fellow, who manages an ambulatory care unit, has set up a process for admitting people with dementia coming into the unit from residential or nursing homes. This was stimulated by an incident when a person had received poor care. For this professional, the Fellowship had '*emphasised the forgotton [sic] many*' so a rapid decision was made to act. Staff now complete a questionnaire over the 'phone with the referring home, so the service is prepared when the person with dementia arrives, and they receive a more supportive response from staff:

> *"It's brought an ease to the process and allows us to resolve problems beforehand."*

Box 10 Example – Improving admission to an ambulatory care unit

The multidisciplinary environment created by the Fellowship built a shared, enhanced understanding of problems with existing pathways, and supported action to resolve these. For example, through discussion with GPs on the programme, one lead nurse became aware that information about patients with possible dementia was not always reaching GPs from the hospital. As a result, they now write personally to every GP when a person with dementia is discharged, setting out what they need to do next, establishing a direct line of communication, and "*narrowing the gap"* between primary and secondary care.

Developments in other settings

Most Dementia Fellows worked either in acute, community or primary care settings. However, a small minority were based in other settings, with one or two in the independent or voluntary sectors. The example below describes the developments that were established by the one fellow who was located in a hospice (Box 11).

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[13] Alzheimer's Society. This is Me. 2010.

Box 11 Example – Improving access to hospice care for people with dementia

One senior hospice manager chose as their improvement project to scope the services that were available in the local area for people with dementia who are at the end of their lives, and for their carers. The Fellowship was timely for them, as dementia was rising up the agenda of the hospice movement at the time. This followed the publication of a report looking at the issue, and there was a debate within the movement about the contribution of hospices towards the care and support of people with dementia and their carers. At the time, the hospice was also developing day services, so an opportunity existed to make sure that these were accessible to people with dementia.

Through the scoping work, they built a number of new partnerships with other organisations, notably the Alzheimer's Society. They partnered with the Alzheimer's Society to establish a dementia café in the hospice. This provided support for people with dementia and their carers, and also brought people into the hospice environment. It was therefore valuable for the organisation in breaking down barriers. The café ran for several months, but ended as a result of organisational issues within the Alzheimer's Society. A support group for the carers of people with dementia now takes place in the hospice. The Alzheimer's Society also collaborated on a dementia awareness event, which brought together a range of organisations that could provide support to people with dementia and their carers. This attracted about 80 members of the public. The event was useful in attracting people into the building, as well as raising awareness and providing information about dementia. Staff and volunteers who deliver day care are now routinely trained to deliver care to people with dementia. The hospice also has a choir, which was set up by the carer of a person with dementia. This now includes carers and people with dementia. It has an ambassadorial role, performing in the community, including nursing homes, so again has the dual role of challenging stigma around both dementia and hospices.

According to hospice data, very few people with dementia access the service, which this fellow suspects may be related to poor coding of secondary diagnoses. During the dementia fellowship discussions about coding did not seem relevant, as clinicians' perspectives dominated. They said:

> *"...but thinking back, we need to improve coding, too!"*

The hospice's Clinical Strategy Group has been an important route for developing the strategic approach to dementia within the hospice. They feel that the element of the programme on influence has been useful in developing their own skills in this area and in increasing effectiveness within the group.

Impact area 3 - Pilot programmes

The previous section illustrates the range of developments carried out by Fellows to improve care for people with dementia. Although it is difficult to assess the extent to which these are embedded into the work of the organisations involved, they were, in the main, intended as long-term changes rather than as pilot projects. The exception is the Golden Ticket initiative (see appended case study G), which was introduced in a single practice, then formally evaluated before being rolled out across the CCG area. This is discussed in the next chapter.

Impact area 4 - Tools and resources

The production of new tools and resources was not a major focus of the Dementia Fellowship. However, a range of resources was developed as part of the improvement work carried out by Fellows. These fall into three broad categories:

- Information for carers
- Clinical tools such as pathway tools and *pro formas*
- Training resources, such as videos

Information for carers

As highlighted earlier, one outcome of the programme's design and content for many Fellows was increased understanding of the key role of carers of people, and the importance of engaging with and supporting them. The sessions on person-centred approaches and on the contribution of carers were crucial in achieving this shift. Two Fellows, both lead nurses in acute trusts, developed information packs for carers of people with dementia. In both cases these have been extended to all carers throughout the hospital.

Clinical tools

Many developments included an element of clinical tool development. For example, the projects that aimed to improve the interface between services produced *pro formas* that represented the framework for proactive conversations such as between an ambulatory care unit and nursing or residential care units.

Training resources

Box 12 Example – A local dementia training film

A lead nurse was about to redesign the trust's dementia training programme when they started the Fellowship. It was the Fellowship, and, as it was put, *thinking laterally*, that enabled them to rethink the training programme completely and make a dementia training film instead. The Fellowship came at exactly the right time with exactly the right content to help achieve this change that has had a wide impact on the trust.

Through the Fellowship, A developed the confidence and skills to take the idea about making a dementia film, and turn it into reality. Colleagues from across the trust in a range of departments collaborated to make the film, and it is now used routinely in induction. The film has also been taken to community settings. They used influencing skills to make the case to the Director of Nursing to secure Dementia Challenge funds.

They took the lead but engendered a sense of local ownership of the project by casting the film with trust staff and carrying out the filming within the hospital. Featured staff included a porter, a ward sister and others. It meant that the film's audience could recognise themselves, their colleagues and the locations.

The fellow has been collecting data to monitor training and was able to show an increase in trained staff from around 74 to 365 in the first year; in the next six months another 600 were trained.

Data on outcomes is so far anecdotal, but the fellow has noticed an increase in awareness amongst staff: *"Even HCAs [Healthcare Assistants] have heard of delirium."*

Chapter 5: Leading strategic and system change

SUMMARY

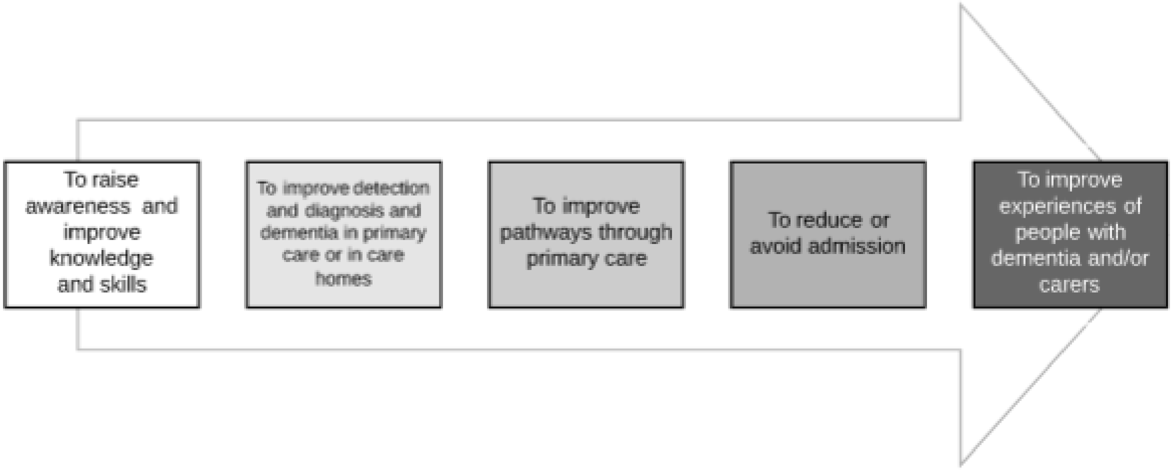
- Dementia Fellows who initiated developments beyond their own service tended to have one or more of four key types of strategic aim:
    - Raising awareness and improving knowledge and skills
    - Improving detection and diagnosis
    - Redesigning or improving pathways
    - Reducing or avoiding hospital admission
- Examples and vignettes frequently highlighted how learning from the Fellowship translated into action
- Strategic changes often involved high levels of influencing skills, working across boundaries, modelling good practice and risk-taking

Through interviews and our case studies, we were able to identify Dementia Fellows who had initiated improvements and changes *beyond* their own practice and immediate service settings. These projects varied in scope, ambition and sustainability but all met the following criteria:

- Resulted partly or wholly from, or inspired by, undertaking the Dementia Fellowship
- Scope involved partners or organisations outside the Fellow's immediate colleagues or own work setting
- Had strategic aims, even if only in pilot form. "Strategic" is defined as seeking to make or lead changes that are grounded in an ambition to affect a *system* of care. Note: minor 'tweaks' to a system were not included in this definition

Dementia Fellows tended to have one or more of four key types of strategic aim, which taken together, demonstrate an overall objective to improve life for people living with dementia, including carers (Figure 7).

Figure 7 - Dementia Fellows making system changes to improve experience for people living with dementia



We now look at some of these aims and initiatives in more detail, focusing on strategic change and leadership skills derived primarily from phase 2 interviews and case studies.

Impact area 1 - Raising awareness and improving knowledge and skills

A number of Fellows cited raising awareness about dementia - including their own awareness - as a key outcome of the Fellowship.

> *"You tend to see the medical aspects, but the course opened up the impact on the person, families, and so on. It's a minefield."* (Doctor)

Fellows talked about taking this learning directly into their practice and taking a lead in sharing it, for example, by incorporating some of the exercises they experienced on the Fellowship in their own training sessions or helping colleagues make sense of unusual behaviour (Box 13).

Box 13 Example - A GP taking the lead in raising awareness with colleagues and care home patients

A GP said the Fellowship raised their awareness about non-medical aspects of dementia. They took the lead in sharing learning in what was described as "thinking laterally" by introducing case study discussions with colleagues.

"Not everything needs to be medicated and I can pass this on, explaining behaviour."

This doctor gave an example of a key piece of learning from the programme during Buz Loveday's person-centred care session: Buz had described a situation in a care home where a resident would always remove their clothes when visitors arrived. It transpired that the person felt the clothes carers had dressed them in were too casual; they had always dressed smartly, in a suit and tie, especially when visitors came. Removing clothes could be better understood once staff were aware of this context for behaviour.

This Fellow has gone on to take a clinical lead role (for planned care) within the CCG.

One GP took a wider system approach to raising others' awareness and skills (Box 14).

Box 14 Example -Taking a system-wide approach to raising awareness and improving experience

This medic has taken dementia awareness and dementia-friendly practice beyond their own GP practice and into the wider system of care. Contributions cover much of the care pathway from A&E through to palliative care:

- Work is done at the local A&E, advocating for patients with dementia who attend the acute hospital
- This GP took a leadership role with their own practice becoming dementia friendly (including an administration lead for dementia and a dementia patient group) and more welcoming to all
- The coding exercise was used to audit and increase diagnosis rates in the own practice and to support other local practices to improve their rates too
- The Fellow encouraged sharing of ideas and interacting between practices
- A care home was newly built close to the practice, and this GP took the opportunity, with practice colleagues, to work with them supporting deprivation of liberty (DOL) training and end of life care for people with dementia

They credited the Dementia Fellowship with giving their work confidence to develop these initiatives.

"When talking to others about what needed to be done, I felt I knew what I was talking about."

On application to the Fellowship, they had sought greater confidence in order to provide excellent care, and the wish to share learning and experience with colleagues across the city; this seems to be exactly what undertaking the Fellowship achieved for this participant.

Among a number of initiatives started after the Dementia Fellowship, another GP, supported change in a local care home by reviewing weight loss in residents, encouraging the use of nutrition tools and aids to better nutrition and introducing a system of notification of weight loss. This work was chosen as a case study for further understanding (Case Study 2) of the critical success factors and the hurdles involved in Fellows implementing wider system change. See box 15.

A GP undertook a change project as part of the programme, using a problem-solving approach. Although this project aimed to improve nutrition in care homes, it had a wider effect as it changed practice in the care home to become more individualised and it resulted in a system change alerting primary care to weight changes in care home residents. Two things motivated the clinician to implement change:

1. There was a noticeable tendency for care homes to request prescription sip feeds without a review of the patient's needs. The Fellow described this as a 'knee-jerk' approach, not individualised, and not proactive. Engaging with the Dementia Fellowship had made the doctor more aware of person-centred approaches
2. There was pressure on prescribing budgets

They decided to work with a local care home (in their role as GP contact). There were several steps to the project, reflecting the plan-do-study-act (PDSA) cycle that was taught on the programme:

- Engaged with key care home staff – the manager and training manager
- Worked with them to see whether residents experienced weight loss after admission to the care home and discovered that 14 of 22 people had lost weight
- Reviewed each of the 14 individuals to determine causes of weight loss and how to address
- Encouraged the care home to introduce the Malnutrition Universal Screening Tool (MUST) and they started to use it routinely
- Initiated a new system whereby a monthly report is generated with the names of people who have lost weight and their MUST score. This can act to proactively support the patient before things deteriorate.

There were several significant outcomes:

- The care home closed for a short while and there was a change of staff, including the manager, but the new system of monthly reporting remains in place
- The MUST tool is still used in the care home. They also use Food First – an approach to improving nutrition that includes elements such as enriched diets, improving availability of healthy nutritious snacks, etc
- The clinician also perceived a reduction in the use of prescriptions of nutritional sip feeds (not measured)

Box 15 Example - Implementing wider system change: Improving nutrition in care homes

Impact area 2 - Improving detection and diagnosis of dementia across a wide area

GPs in particular were keen to improve detection and diagnosis of dementia in primary care as discussed in Chapter 4. Two factors provided motivation for improving diagnosis rates: firstly, the national policy agenda, and secondly, the coding exercise introduced by the Dementia Fellowship as an exemplar to encourage physicians to improve diagnosis rates in the first two cohorts, as already mentioned. This chapter focuses on examples of Fellows who took the coding exercise beyond their own practice to a wider patch, where one GP achieved impressive results (Box 16).

Although GPs were, understandably, the most likely profession to be involved in improving detection and diagnosis, nurses were also key players. One nurse working in a commissioning role, also took a strategic approach to improving detection and diagnosis, working with local GP practices to identify people whose diagnosis may have been missed and supporting the set up of additional support for the population of people with dementia. This nurse ensured data was up to date and refreshable. They were also involved in developing a CCG-wide dementia strategy looking at the whole pathway including early recognition through to putting lasting power of attorney arrangements in place. They felt the Dementia Fellowship had a critical influence in building confidence to undertake this work and to develop their skills:

> *"It definitely influenced me, my style. It made me more aware. It helped me reflect and introduced me to various [leadership] tools."* (Nurse/commissioner)

Another nurse also found the experience on the Fellowship gave them tools to think differently and more strategically about diagnosis:

> *"If I hadn't done the course, I'd have seen [diagnosis coding] as a tick box exercise. Now it's about how to understand what's going on, make sure the right people are in the right place to provide care. If you know that around 80% of care home residents have dementia, have we got enough services that are supporting those people? It helped me identify the gaps."* (Nurse)

Having already noted poor diagnosis rates in their own practice and within the locality, one lead GP, initiated a project to improve dementia diagnosis across the CCG area. They were able to demonstrate a more than 50% improvement in the rate of diagnosis within the patch, from prevalence rates of 44% to 67%.

They used a number of key change management tools:

- Persuasion and influencing
    - the CCG were convinced to accept a few relevant READ codes for dementia rather than deal with the range of complex codes that could be used (this idea came directly from the GP attending the Fellowship)
    - they then worked with GPs across the patch, demonstrating how the coding could make things easier for them
- Building relationships and identifying allies
    - After writing to each practice, the GP made sure the letter came from the CCG and ensuring the Practice Manager was also one of the recipients
    - Individual visits were made to GPs, practices and care homes to explain how things could be easier for them and the financial and quality incentives
    - Coding simplification was discussed with the Memory Assessment Service consultant to get agreement and co-operation between primary and secondary care
- Modelling good practice
    - Care home case notes were seen personally to identify people who might have dementia but had not been diagnosed, advised staff about questions they could ask themselves by introducing a bespoke tool, and then supported them to bring individuals to the attention of GPs
- Use of data
    - They made the CCG aware of poor rates
    - Comparative data was used to show practices where they stood in relation to other practices in the area
    - Active monitoring took place so that when, for example, a practice's prevalence rate suddenly dropped they were able to spot it, visit and find out why

Box 16 Example - Improving diagnosis rates in primary care and care homes

Impact area 3 - Improving pathways through primary care

A few Dementia Fellows took on the strategic task of improving local pathways through primary care for people living with dementia. One CCG's Dementia Lead tackled this across the CCG by working closely with primary and secondary care colleagues (Box 17).

A GP dementia lead for a CCG heard from families living with dementia, and from primary care colleagues, that there were problems with the dementia pathway. Without a diagnosis, patients could not get care and treatment from secondary care dementia services - but only secondary care services could diagnose: a Catch-22 situation.

So they worked with both primary care and secondary care colleagues to get an agreement that GPs could make dementia diagnoses, and that with this diagnosis, patients could access primary care. This involved changing GP practice, training and using leadership skills to persuade both primary and secondary care to sign up to the new way of working. This Fellow identified the benefits to all parties:

"Well the beauty was this was an obvious solution. I was given a slot on training day. If you want to access services, GPs, you put your name to dementia diagnosis and I guarantee that secondary services will accept. "

The doctor liaised with secondary care, listened to them and supported them. And also provided feedback:

"I'm pleased to say there are no more complaints about access to the pathway."

Box 17 Example - Working with primary and secondary care to improve pathways

Impact area 4 - Reducing or avoiding admission

An aim to reduce or avoid hospital admission was a particular concern for specialist dementia nurses working in community settings, and was indeed often an explicitly stated component of their role. Nurse Fellows said that the Fellowship supported them in taking a more strategic approach to implementing admission avoidance initiatives. For example, one nurse said that before attending the Dementia Fellowship, they would have gone into individual care homes to address issues; since the Fellowship they now see problems are system-wide and need system-wide solutions.

In one of the phase 2 interviews, a community-based nurse talked about the work they had done to reduce admission (Box 18).

Box 18 Example - A community nurse working to reduce admission across two clinical commissioning groups

One nurse work across two CCGs to avoid unnecessary admission to hospital. In this patch there were around 150 care homes. There was enormous pressure on local acute hospitals, described as frequently "on black alert."

This nurse worked with a commissioning colleague to establish a dashboard, identifying the care homes that were sending most patients into hospital. They focused on working with these homes and looked at their last three months' data to identify and review the patients who had gone into hospital. This enabled all those involved to understand why admissions had taken place and in doing so; identify support to the care homes to make improvements.

Some issues were identified as about working proactively – care home staff were not always detecting early problems or signs of deterioration until these became a crisis. Staff were supported to work up anticipatory care plans.

Other concerns were about getting support for key physical health conditions, such as infections, cardiac and respiratory issues, and delirium. This nurse worked with the consultant geriatrician and secured agreement to review people with complex conditions.

They reviewed admissions data and were able to show that care home admissions reduced. An operational group comprised of key people including commissioners and clinicians was set up, and presented monthly data and patient stories to this group. As a result, funding was made available for another clinical nurse specialist post.

Aspirations for the Fellowship had been relatively modest: to improve knowledge and skills to support care homes more effectively and to set up hubs to support learning across their area. But there was little suggestion that they were thinking about developing leadership skills. On coming on to the course, they were initially daunted.

"I thought it would be more clinical. But it was very clear from the start that this was around a much wider agenda. I walked into a room of GPs and almost turned round and walked out again. I was pleasantly surprised that it would help me with some of the issues I'd been struggling with… For me, it was amazing. It changed me."

This Fellow has now been appointed to a new Head of Service job; the experience in reducing admissions and the learning from the Dementia Fellowship supported the appointment.

In West Sussex, three community nurse specialists undertook the Fellowship together. They had a specific remit to reduce hospital admissions from care homes (Box 19).

Three community dementia nurse specialists in a community trust had a specific remit to reduce hospital admissions from care homes. They work with the ten care homes that each month sends the most people to hospital, offering training and support.

Following the Dementia Fellowship, one of them developed a pathway for care homes to use, with the following features:

- Flow charts around different types of behaviour or presentation change
- Guidance about what might be the reason for someone's presentation to change
- Specific and easy to follow guidance about delirium
- Phone numbers of people to contact for specialist help

Care home feedback has been positive and other colleagues have also said how useful the care pathway is.

All three specialist nurses had aspirations to improve practice and care and felt they achieved much through the Fellowship, although one nurse wanted more advanced knowledge and skills from the Fellowship. Nevertheless all felt that the Fellowship gave them new skills and a sense of "permission" to develop their roles and perspectives: *"We all talk about the bigger picture now."*

Box 19 Example - Three community nurse Dementia Fellows working together to reduce care home admissions

Chapter 6: Factors in implementing change

SUMMARY

A number of mainly contextual factors influenced the ability of Fellows to effectively implement changes in practice:

- The work environment, and especially, the freedoms and restrictions associated with professional roles
- Changing culture
- Sharing learning
- Measuring impact

Interviews with Fellows highlighted several broad themes related to the factors that influenced the extent to which they were able to bring about change. These themes are discussed below, and include:

- The work environment
- Changing culture
- Sharing learning
- Measuring impact

The work environment

Where people were working in strong autonomous roles (such as GPs), and especially if they had recognised lead roles, they were able to influence strategic change. However, for some, taking up authority in an environment that can be disempowering was a big hurdle to overcome. This was particularly the case for Fellows whose roles did not bring automatic authority or who were working in large organisations (such as large trusts). Some felt the changes they wanted to make simply could not be heard or they did not have access to the right people:

> *"Decisions are made on high, and we have to do what we're told."* (Nurse)

Others were able to use the skills, confidence and impetus from the Fellowship to overcome potential organisational barriers. One nurse remarked that their best advice to others would be:

> *"Get the right people around the table that can make change… [people with] influencing skills [who] understand what's needed in the locality."* (Nurse)

One Fellow suggested that it might have been helpful to have a requirement for applicants to the Fellowship to have a sponsor, or a commissioner or manager, who would commit to support the applicant to develop their roles or make service change.

Changing culture

Culture change was a challenge for a number of Fellows trying to make change, especially across systems. For example, there was recognition that encouraging fellow GPs and even CCGs to improve diagnosis required a cultural shift, despite national directives; some interviewees said they had encountered ‘resistance’ among colleagues:

> *““There was a lot of email traffic saying: “Is blissful ignorance better?” “There’s no advantage to early diagnosis.””* (GP)

Dementia Fellows who had worked at improving diagnosis rates fully appreciated that diagnosis on its own was not an objective; rather, there was a need for diagnosis to ensure people got the best treatment, care and options for their futures.

> *“It’s not just about finding everyone we can with dementia. It’s not just the diagnosis that makes the difference.”* (Nurse Commissioner)

The issue for Fellows was how to get this message across to colleagues:

> *“It took six or seven months to raise awareness among our GPs…. It’s even more difficult with care homes. There are financial consequences.”* (GP)

Sharing learning

As noted above, several Fellows commented that they would have valued some level of on-going support from the Dementia Fellowship team to help them continue to improve, learn and share experience. This was a longer term aspiration for the team, whose primary focus was on delivering the programme to four cohorts within a relatively short period of time, in order to extend the learning as rapidly as possible across Kent, Surrey and Sussex.

Some of the specialist nurses did link up with each other, largely through the initiative of one of them and found this very supportive. Although the network no longer meets formally, a core group still keep in contact with each other and find it useful to be able to call on other specialist nurses for advice or support. However, there was no (perceived) support from the Fellowship to enable and maintain professional networks.

Although Dementia Fellows appreciated the existence of the networking conferences, not everyone could attend on a given day and they felt that there needed to be more support to keep people connected:

> *“I have struggled to attend the networking days and my links with the rest of the group have disappeared.” (GP)*

> *“It would be helpful to have a central hub, even a website with interesting ideas. I’d have liked to keep in touch with people.”* (GP)

> *“[Even though] there is a Facebook page, there’s not much going on there. It could be more active. And anyway, is Facebook the right place?”* (Hospital doctor)

Linked but slightly different was one person’s opinion that the Fellowship could support participants further to become involved in important existing local and national networks (such as the regional Strategic Clinical Network for Dementia).

Measuring impact

A few Fellows collected data to monitor whether or not their initiatives had made a difference. Mostly this was relatively accessible quantitative data, such as diagnosis rates. The data supported the changes, and could be used by Fellows to encourage colleagues to continue or take up the initiatives (such as coding). We found few examples of Fellows collecting a wider range of data, but the Golden Ticket (a pilot that was independently evaluated) used both qualitative and quantitative data, including for example, diagnosis rates, hospital admission rates and carer feedback. The data has helped persuade funders and commissioners to sustain and expand the work.

However, some Fellows did not collect data at all, and this has left them and their work vulnerable and may also have contributed to lack of spread:

> *“We don’t record…. We don’t systematically get feedback…. We thought we’d spread our expertise but it hasn’t happened.”* (Nurse)

Section Four- Conclusions

Chapter 7: Discussion and conclusions

Introduction

This chapter summarises and discusses the findings of the evaluation, using the Darzi evaluation principles of successful leadership programme design as a framework to discuss our key messages about the Dementia Fellowship.

Summary of findings

Clarity of purpose and aims

> *"From leadership and change management to the clinical knowledge that Sube brought…"* (GP)
>
> *" We're part of a Fellowship – shouldn't we all be doing things? Who's challenging us? "* (Nurse)

The leaders of the Dementia Fellowship were clear that the programme was designed as more than a training course on the clinical aspects of dementia. All the publicity materials and literature relating to the Fellowship contained a description of the programme that emphasised the parallel elements of leadership development and service improvement, although this third strand strengthened over time. In addition, there was an explicit aspiration to create a sustainable network of people with a shared commitment to improving services for people with dementia across Kent, Surrey and Sussex.

In the main, Fellows recognised and valued the broader purpose and aims of the programme. One or two questioned what it meant to be part of a Fellowship, and expressed a slight disappointment that the strong relationships forged during the programme had not yet led to collective action to improve services or influence national policy.

Mutuality of workplace and external learning – timing/synchronicity

> *"Nobody taught me how to do it until the Fellowship. It came at the right time!"* (GP)

The Fellows who managed to achieve significant change were often aware that they needed to do something to improve care for people with dementia in their organisation or system, but before they joined the programme they were not clear what this should be. The Fellowship provided information on current best practice, and also helped to develop the skills to introduce change. Timeliness, and synchronicity between the goals of the programme and individual or organisational priorities increased the chances of success.

Learning for transformational change

> *"Bringing together clinical knowledge with leadership and improvement tools achieves epiphany moments."* (Fellowship team member)

> *“Realising that within every person with dementia there’s a person, not a tick box.”* (GP)

For the majority of Fellows, the Fellowship resulted in transformational change at several levels. The ‘mind shift’ identified as part of the evaluation of the London Darzi Fellowship programme related to new understanding of the role of clinicians in achieving change. Many Dementia Fellows also described a similar revelatory shift at a personal level, but in different areas, including:

- For all professional groups, genuinely understanding the meaning of person-centred care for people with dementia
- For all groups, understanding the key role played by carers in acting as a bridge to the person
- For GPs, understanding that they were not solely responsible for all aspects of care – they form part of a wider care system in which other professionals and resources have a contribution to make
- For nurses, understanding that they had an important role, expertise and leadership potential

Ambitious but doable projects

> *“The scope (of improvement projects) was very variable – it was down to them.”* (Fellowship team member)

The improvement projects that Fellows developed during the programme varied enormously in terms of their scale and scope, from system-wide transformation in a geographical area to more modest changes to a process within a single practice. Fellows were responsible for the design of projects, so the variation is not surprising, given the diversity of their roles and professional backgrounds. Some Fellows seemed to take their improvement projects more seriously than others, although there were some notable successes (described earlier in this report).

Organisational context: Committed and learning-oriented sponsors, and supportive organisational culture

> *”It’s difficult here. There’s been a change in leadership and management, there’s no strategic leadership.”* (Nurse)
>
> *“There’s no way (the Golden Ticket) would have happened without the CCG fully behind it.”* (GP/Commissioner)

Some Fellows encountered organisational obstacles to bringing about change for people with dementia. This was a particular issue for staff in non-specialist roles in acute trusts, and for the small number of therapists who were involved in the evaluation. For these groups, difficult organisational environments, often in trusts facing extreme financial and performance challenges, combined with no explicit service improvement responsibilities, meant that they struggled to achieve change. This was not a universal finding, however, as some non-specialists overcame these difficulties and implemented important service improvements.

For other Fellows, a supportive organisational context was key. Both the Golden Ticket, and the developments described in case study E, were underpinned by support from the host organisation.

Unlike the London Darzi Fellowship, organisational sponsorship did not appear to be a strong element of the programme, and we did not find evidence that it was a factor in the Dementia Fellowship.

High quality mentoring

> *"I felt like somebody was holding my hand. I've never had that, ever. It was just fabulous. It just doesn't happen."* (GP/Commissioner)

The London Darzi Fellows all had a senior level mentor in their home trust to help them embed and implement their learning. This was not the case with the Dementia Fellowship. However, a group of Fellows mentioned the importance of the support they had received from the central team, and this informal mentoring played a central role in enabling them to implement change.

Network of supportive peers

> *"The network is absolutely brilliant. I set up the first meeting. I took the leadership I was learning."* (Nurse)

The development of a sustainable network was one of the goals of the Dementia Fellowship. A group of nurses who attended the first cohort set up a network that continued meeting in person for about a year after the end of the programme. Over time, practical considerations, such as the distance between the nurses' bases, and competing pressures within their trusts, meant that regular meetings came to an end. The group still keeps in touch informally, acting as a source of advice, information and mutual support.

As noted previously, during the programme, the relationships that developed between Fellows had a key role in increasing both knowledge and confidence. One to two years after attending the programme, though, few Fellows seemed still to be in contact, other than those who were working together on a discrete initiative, or who were based in the same organisation.

Diversity of participants

> *"In trusts, you're isolated in your bubble. It's nice to hear what others are doing. Inspirational."* (Hospital doctor)

> *"Everyone brought something to the table. And multidisciplinary – this is the way of the future."* (GP)

Sharing experience and solving problems alongside other Fellows was a highly valued aspect of the programme. Many Fellows commented on the importance of the multidisciplinary mix of the cohorts (particularly cohorts 1 and 3, as cohort 2 was focused primarily on GPs). Fellows appreciated learning about the contrasting professional worlds occupied by others, and the respective contributions different groups make to the care of people with dementia. This was more than an interesting exercise, as the bringing together of different professional groups broke down barriers in understanding and communication, and enabled Fellows to think creatively about creating integrated pathways for people with dementia.

On going monitoring and adaptation

> *"There was a leap forward in thinking between cohorts 1 and 2. (We realised) it needed to be more than clinical stuff and leadership."* (Fellowship team member)

Programme design evolved over time. The service improvement element grew stronger and more explicit. Also, Fellows from earlier cohorts presented their work to later ones, providing inspiration and demonstrating what could be achieved.

Planning for sustainability

This was an explicit goal of the evaluation, and is addressed in the recommendations, below.

Tracking impact over time

This evaluation is the first formal follow up process that has aimed to track the impact of the programme.

Section Five- Recommendations

This section sets out a series of recommendations and brings together the learning about how best to design and deliver similar programmes in the future. Recommendations are clustered in to two themes. First are five recommendations for the redelivery of another cohort of the Dementia Fellowship Programme. Second are recommendations about the structure, delivery team mix, core principles for content and implementation, as well ways in which to optimise programme impact.

Chapter 8: Recommendations

Recommendations for the Dementia Fellowship Programme

1. Complete and issue the evaluation, conclusions and recommendations

2. Identify what further support and advice to Fellows would optimise their impact at the three levels of:

    a) Individuals' professional practice
    b) Specific individual service areas
    c) Wider healthcare systems and patient pathways

3. Publicise, share and network good practice through a central website, and dedicated social media, offering a platform for short videos, blogs, webinars and news posts to spread the learning

4. Focus on the implementation and spread of good practice, offering practical coaching, implementation advice, problem solving and learning support to develop and implement local initiatives

5. Support to Dementia Fellowships 'local' – for example, Dementia Fellowship faculty partnering local rollout of good initiatives (e.g. current pilot of support to the Golden Ticket to achieve wave 1 and wave 2 implementation in East Sussex)

Recommendations for others developing dementia leadership programmes

6. Achieve the right mix of participants – also consider finding ways of extending beyond the NHS to social care and the care home sector to support a system-wide response

7. Ensure that the delivery team reflects a similar diversity of skills, professional background and personal experience

8. Build into the programme design as a core principle an integrated approach to offering clinical knowledge, leadership skills for change, and service improvement skills

9. Bring in the lived experience of dementia for individuals, families and carers as a central theme

10. Base the programme in opportunities to build networks and encourage shared problem solving

11. Learn from a valued feature of the Dementia Fellowship Programme design. Offer residential blocks that allow time for reflection, network building and sharing stories of implementation

12. Provide on going support post-programme to maintain momentum and focus

13. Create opportunities to feed learning from Fellowship upwards and outwards to influence service development and policy debate

14. Consider how best to target the programme to maximise impact

Appendices

Appendix A: Overview of Dementia Fellowship Programme structure

Cohort focus and date	Key additional elements
Cohort 1 – Targeted primarily at primary care March – June 2014	**Jeremy Hughes**, Chief Executive Officer, Alzheimer's Society **Eleanor Bateman**, Lambeth & Southwark CCGs Commissioning – service improvement case study **Buz Loveday**, person-centred interventions
Cohort 2 – Targeted primarily at primary care May – October 2014	**Dr Laura Hill**, GP, Crawley CCG – dementia friendly Crawley **Jessie Cunnett**, Patient and Public Involvement Solutions – engaging with patients and public **Buz Loveday**, person-centred interventions
Cohort 3 – Targeted primarily at urgent/acute care February - April 2015	**Dr Geoff Bryant**, BSUHT – Urgent and emergency care **Buz Loveday**, Person-centred interventions **Professor Rowan Harwood**, Nottingham University Hospitals Trust - People with mental health problems in the hospital setting Screening of **Alive Inside** (pm session) – with Lucy Frost (cohort 1) **Rachel Thompson**, Professional and Practice Development Lead, Admiral Nursing with Dementia UK - Changing the culture of care for people living with Dementia **Vicki Leah**, Nurse Consultant, University College London Hospital - multidisciplinary care within the acute hospital **Ladder to the Moon Theatre Company** (pm session) **Dr Elizabeth Gill** (cohort 1) and Kim Grosvenor, Lewes and High Weald CCG - Improving dementia care in primary and community settings

Appendix B: Supporting clinical leaders to achieve change – the evidence

Recent national frameworks for action on leadership and improvement in NHS funded services[14] emphasise the continuing need for support on improvement skills and leadership development as health systems navigate the current organisational and financial turbulence.

A 2015 King's Fund review of the evidence relating to leadership development interventions in health found that:

> ***Overall, the evidence for the effectiveness of specific leadership development programmes within the NHS is highly variable and little robust evidence has been accumulated...***
>
> ***Undoubtedly some programmes work for some people some of the time and the need to ensure effective leadership is clear, but evaluating their effectiveness empirically is challenging and demonstrating positive effects on patient outcomes has proved elusive[15].***

The review did highlight a small number of programmes that appear to show evidence of a positive impact, primarily on the practice and behaviour of individual participants. These include the Royal College of Nursing's Clinical Leadership Programme, and the NHS London Darzi Fellowships in Clinical Leadership Programme, learning from which is summarised below. Several facilitating factors characterise the more successful programmes, including:

- Clear learning objectives and content
- Appropriate sequencing
- Delivery that uses a mix of methods
- An opportunity to practice what has been learned
- Feedback that helps to build the confidence of participants
- Follow up activities back in the home organisation
- Opportunities to reflect on progress

The design and approach of the Dementia Fellowship were influenced by the faculty team's experience of the design and delivery of an earlier London SHA programme, where they had aimed to develop GP leaders in improving dementia care. The Fellowship's leaders had designed and led this initiative in 2012/13, the design of which was informed by the team's former experience at The Kings Fund of leading the NHS London Darzi Fellowship Programme. The Darzi Fellowship was designed for early career doctors, and the programme combined carrying out local service improvement projects, supported by mentoring from a senior clinician in their home

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[14] The National Improvement and Leadership Development Board. Developing People Improving Care. UK. 2016.

[15] King's Fund, Leadership and Leadership Development in Health Care: The Evidence Base. London: King's Fund. 2015.

trust, with attending a leadership development programme. The Institute of Education published an evaluation of the Darzi Programme in 2010[16]. This offers useful frameworks and models that have been applied subsequently to the evaluation of similar programmes, including, for example, Cardiff University's 2014 evaluation of a clinical leadership fellowship programme in Wales[17].

The Institute of Education found that the Darzi Fellows had experienced a 'mind shift' in their understanding of the role of clinicians in leading change, with a significant personal impact across six areas:

- Growth in self-understanding and personal skills
- Increased knowledge and understanding of the organisation and system context of change
- Enhanced understanding and skills in working with others
- Change management, service improvement and capacity building knowledge, understanding and skills
- Changed beliefs and values
- Changed career aspirations

The evaluation also identified the impact that Darzi Fellows were making within their trusts, and highlights examples of service improvement projects or training developments. At a system level, the evaluators concluded that it was early days for change to be embedded, but potential existed for the future.

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[16] Institute of Education, 'Mind shift' An evaluation of the NHS London 'Darzi' Fellowship Programme. London: Institute of Education; 2010.

[17] Bullock A., Phillips, S., Evaluation of Welsh Clinical Leadership Training Fellowship Programme. Cardiff: Cardiff University1 School of Social Sciences; 2014.

Appendix C: Evaluation design and methodology

The evaluation was commissioned after the end of cohort 3 so a post-hoc design was used. We focused on the following four main sources of data as described in the table above:

1. Telephone semi-structured interviews (Phase 1 interviews)
   We aimed to interview the full sample of Fellows who had undergone the training for an overview of their experience, learning and outcomes. We offered phone interviews of up to half an hour, with as flexible a timetable as possible, in order to reach the maximum number of Fellows. Fellows were contacted initially by the Dementia Fellowship team and invited to take part in the evaluation. Fellows who did not respond to the initial invitation were prompted at various points by the Dementia Fellowship team.

2. Follow-up face-to-face semi-structured interviews (Phase 2 interviews).
   A sample of Fellows were selected for more in-depth face-to-face interviews if, during the phase 1 interview, they had mentioned interesting changes or challenges that might warrant further investigation and provide further valuable information to answer our evaluation questions. For phase 2 interviews, Fellows were contacted directly by the evaluation team.

3. Case studies (Phase 3)
   This involved a very small sample of Fellows, selected in discussion with the Dementia Fellowship team; on the basis that the changes or improvements that they had made or attempted could provide more comprehensive data about implementing improved dementia care beyond individual practice. Case studies included follow up face-to-face interviews with Fellows, meetings and interviews with colleagues and non-participant observation of work groups.

4. Document review
   Documentation and records kept and collated by the Dementia Fellowship team, including initial applications, poster presentations and module evaluations, were used to supplement interviews and case studies.

In addition to these key sources of data, we:

- Interviewed the Dementia Fellowship team
- Interviewed the lead for Kent, Surrey and Sussex dementia clinical network
- Reviewed relevant national and local dementia policy documentation

Copies of interview schedules are available from the evaluation team.

Table 3 shows the data sources for addressing the evaluation questions:

Table 3 - Evaluation data sources

Evaluation questions	**Source 1** Documentation	**Source 2** Phase 1 interviews	**Source 3** Phase 2 interviews	**Source 4** Case studies
Fellows' experience of the programme	✓	✓		
General change and development	✓	✓		
Learning new skills and knowledge		✓		
Improved own dementia practice		✓		
Improved dementia care beyond own practice		✓	✓	✓
Improved leadership and change management			✓	✓
Critical success factors in implementing dementia care improvements			✓	✓
Learning for other training course developers		✓	✓	✓

Appendix D: Overview of Dementia Fellows and Evaluation Sample

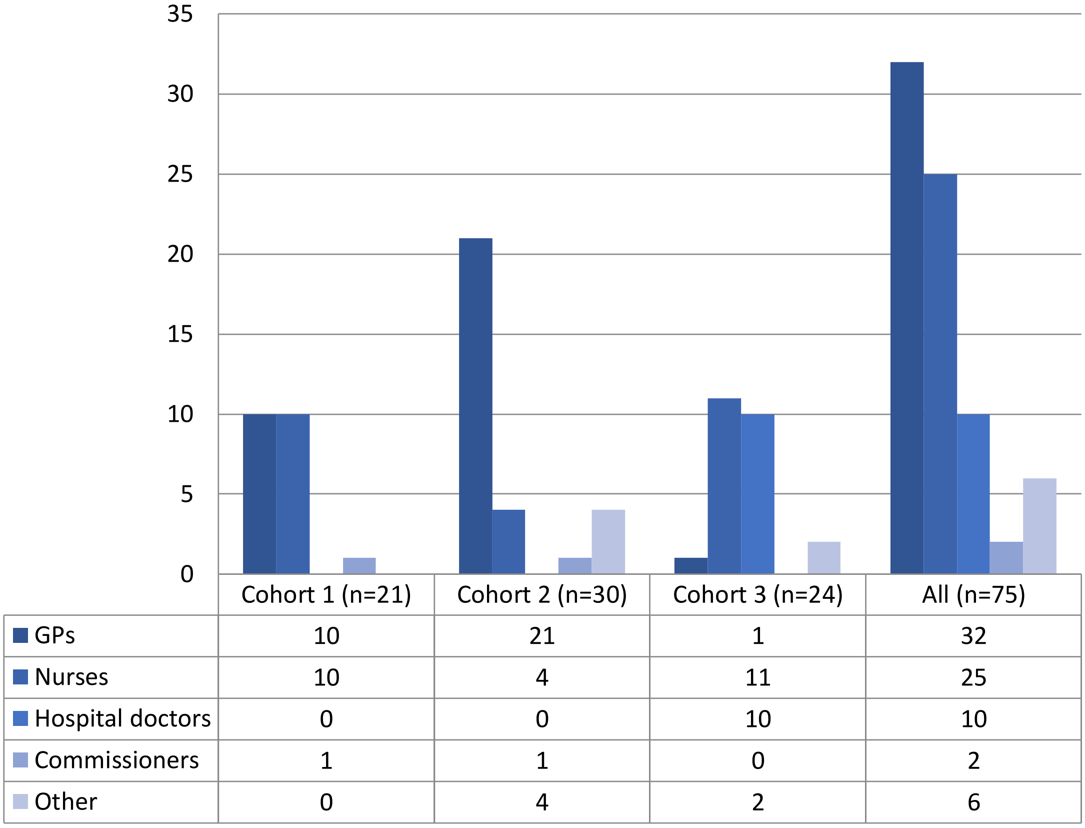
Dementia Fellows – Population description

There were 75 participants in the Dementia Fellowship across the three cohorts:

- Cohort 1 – 21 participants
- Cohort 2 – 30 participants
- Cohort 3 – 24 participants

Tables 1 and 2 give a breakdown of the cohorts by profession and location. The biggest professional group of participants were GPs (n=32, 42.7%) with a sizeable proportion of nurses from both hospital and community settings (n=25, 33.4%). The 'other group' included allied health professionals and commissioners. Almost half of participants were based in Sussex (n= 35, 46.7%).

Figure 8 - Full sample of Dementia Fellows by cohort and profession

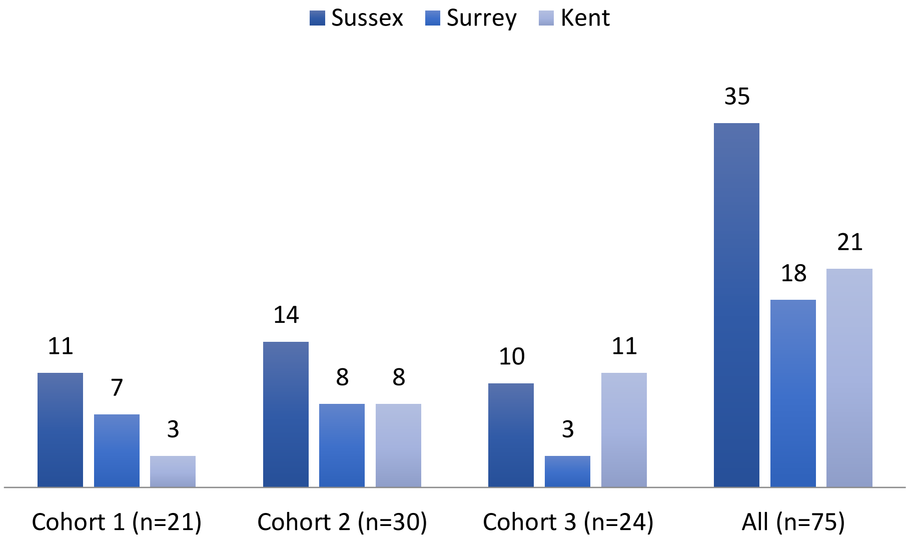


	Cohort 1 (n=21)	Cohort 2 (n=30)	Cohort 3 (n=24)	All (n=75)
■ GPs	10	21	1	32
■ Nurses	10	4	11	25
■ Hospital doctors	0	0	10	10
■ Commissioners	1	1	0	2
■ Other	0	4	2	6

However, the cohorts varied considerably in terms of both professional profiles and locations. This variation in professions was largely a result of recruitment policy on the part of the Dementia Fellowship team. When the first course was advertised, a diverse range of practitioners applied, which resulted in a mixed group. The Dementia Fellowship team took a decision to target GPs in the second cohort, reflecting policy drivers to improve detection and diagnosis in primary care. GPs therefore account for 21 of 30 Fellows in cohort 2. For the third cohort, there was an aim to improve hospital and emergency care, resulting in more hospital doctors in this cohort (10 of 24), although, in fact, this group had the highest proportion of nurses (11 out of 24), many of whom were community-based.

Similarly, the Dementia Fellowship team made a concerted effort to attract more applicants from Kent, following the first cohort when there was only a small number of Kent participants. This resulted in an increase from only 3 participants from Kent in cohort 1, to 11 by cohort 3.

Figure 9 - Full sample of Dementia Fellows by cohort and location



Dementia Fellows – the evaluation sample

Figures 10 to 12, below, give a breakdown of the 44 Fellows by cohort, profession and location.

Figure 10 - Interview sample by cohort

Cohort	Interviewed (% of sample interviewed)	Total in cohort (% of total population)	% of cohort interviewed
1	14 (32%)	21 (28%)	66.7%
2	14 (32%)	30 (40%)	46.7%
3	16 (36%)	24 (32%)	66.7%
Total	44 (100%)	75 (100%)	58.7%

Figure 11 - Interview sample by location

Location	Interviewed (% of sample interviewed)	Total in cohort (% of total population)	% of DFs in that location interviewed
Surrey	7 (16%)	18 (24%0	39.0%
Sussex	26 (59%)	35 (47%)	74.0%
Kent	11 (36%)	21 (28%)	52.0%
Total	44 (100%)	75 (100%)	58.7%

Figure 12 - Interview population by profession

Profession	Interviewed (% of sample interviewed)	Total in cohort (% of total population)	% of DFs in that location interviewed
GPs	17 (39%)	32 (43%)	53.0%
Nurses	18 (41%)	25 (33%)	72.0%
Hospital doctors	5 (11%)	10 (13%)	50.0%
Other	4 (1%)	8 (1%)	50.0%
Total	44 (100%)	75 (100%)	58.7%

Appendix E: Case Studies

1. A leadership development journey
2. Leadership across organisational boundaries
3. Leading holistic improvement in dementia care

Case Study 1

A leadership development journey

Background and rationale for case study

At the time this participant started the Dementia Fellowship, the Fellow was the lead dementia nurse at an acute hospital trust, In 2015, after completing the Fellowship, they took up a nurse consultant role at a community trust with a more senior strategic remit in relation to dementia.

In applying for the Fellowship, they expressed the following aspirations to:

- Improve integration between primary and secondary care
- Understand priorities and challenges in commissioning and developing better care
- Develop knowledge on dementia care and how to improve it
- Strengthen skills in engaging with the public

This case study sets out the impact that the Dementia Fellowship has had on the person at the three levels explored by the evaluation: individual, service and system.

The Impact of the Dementia Fellowship

What was the impact of the Dementia Fellowship on the Fellow as an individual?

Self-understanding and personal skills

Previously, this nurse had at times taken on too much, with competing priorities. Skills gained on the programme enabled them to feel more in control of their workload by managing better and prioritising more effectively: *"Ever since the DF I have a work plan."*

The Fellowship also equipped this person to make the transition from practitioner to strategic leader, which was personally challenging:

> *"It's a really difficult transition to make. I really, really miss contact with people (with dementia)."*

Organisation and system context of change

Continuing to learn how to behave in an organisational context to make change happen, for example by managing upwards was on going for this attendee. Although they still find it frustrating that time needs to be spent honing political intelligence, *"the Dementia Fellowship started to sew those seeds"*. During the Fellowship, confidence grew to operate at a strategic level, and is still developing and now aspires to bring together work on dementia across the trust.

Working with others

Through the ‘Alive Inside’ programme, described below, this Fellow has developed close links with a range of organisations and people outside the NHS, has brokered new connections, and has identified shared interests and concerns.

> *“[the fellow] is a key part of connecting people, being a voice on the radio that people can understand” (*Film-maker)

> *“…[the Fellow] is a great networker, great on social media, good at linking people up with people.”* (Musician)

Change management, service improvement and capacity building

> *“The Fellowship made [the Fellow] step back and think strategically about the wider context.”* (former manager)

> *“(The Fellowship) gave us a toolkit to go away and lead improvements.”* (Nurse)

This nurse’s former line manager commented that as a result of the Fellowship, they had observed them starting to look at how to do things differently and to work smarter with the resources that existed, both within the trust and outside it. This broader approach is highlighted by the work with Alive Inside.

Beliefs and values

Since the DF, they have been much more thoughtful about how best to make sure that people with dementia and their families are engaged properly. Colleagues have given the Fellow feedback that they model a person-centred approach to care. Alive Inside partners endorsed this too. The training programme at the acute trust included a strong focus on how it feels to have dementia, as a direct result of their learning on the programme.

> *“How do I make sure that people’s voices are heard? The Dementia Fellowship gets you thinking more deeply about what person-centred care really is.”* (Fellow)

Revised career aspirations

As for many of the Fellows, confidence improved as a result of the Fellowship. Following the programme they were successful in getting a new post that was considerably more senior than their existing role – “*Confidence gained from the DF told me ‘Go for it!’*”

What was the impact of the Dementia Fellowship – leading change within a service?

> *“The Fellowship gave me the skills set to develop an education programme.”*

A strategic role has enabled key pieces of work on staff training and strategic development. At the acute trust, this nurse has led the design of a new corporate education programme, which they describe as “*systematic, strategic and explicitly linked to outcomes.”* The programme is delivered in partnership with an external, non-clinical provider, which uses simulation techniques and person-centred approaches. Feedback from participants is that the training is transformative, and has changed their perceptions, as well as the way in which they care for people with dementia (and the Fellow has observed better interactions with people with dementia).

> *"In my new job I wrote the strategy, identified the gaps in the pathway. It was a complex piece of strategic planning and I wouldn't have been able to do it without the skills gleaned on the Dementia Fellowship." (DFP participant)*

The new role gave this nurse increased strategic responsibility, which was a new area. The programme enabled this work.

Leading strategic and system change

> *"Alive Inside gave me the confidence to do my job in a different way."*
>
> *"…[the Fellow] has a strategic vision … that's what sets them apart*." (Musician)

Since the Fellowship, this nurse has developed a strand of work using arts and culture as a method for developing staff and engaging the community to increase understanding and awareness of dementia. The nurse worked with a local filmmaker (introduced by the Dementia Fellowship team) to set up a series of screenings of Alive Inside, a US film on the impact of music on people with dementia. Although the initial intention was that the screenings should form part of the Trust training programme for staff, it was soon decided to open them up to people with dementia and their carers, and to the local community. The idea of bringing the film out into a community venue and extending the invitation widely meant that a very broad range of people shared the experience and the sessions have become a vehicle for greater integration and shared understanding.

> *"Audiences were really moved. Everyone wanted to share stories. There were musicians in the room, therapists, care home staff, choir members. It touched lots of different parts of the community."* (Filmmaker)

Screenings are usually introduced by a guest speaker (including writer and campaigner, Nicci Gerrard[18] and SB, as well as the nurse) and followed by a facilitated discussion. 15 screenings had taken place by late 2016, including a screening as part of Brighton's Fringe festival. The work has taken on a momentum of its own, with screenings continuing to take place. Feedback has been very positive. The audience members are asked to make a commitment to act, and follow up actions have included people buying iPods for care homes.

> *"The reach was far beyond anything I'd hoped to achieve."*

Critical success factors

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[18] The King's Fund. Insight Magazine. Dementia: A Carer's Perspective. 2015

The Dementia Fellowship appears to have been an important experience for this nurse. The three critical success factors, which this story highlights, include:

Personal qualities

The nurse's former line manager identified them as a potential 'high flier' at interview, and there was clearly a high level of readiness for learning, development, and change. Since the Fellowship, this Fellow has taken on additional opportunities that have enabled continuous development. In addition, interviewees highlighted their preferred working style, which involves brokering connections between people and groups. This was essential in leading the initiatives described above.

Access to development through the Dementia Fellowship

The Fellowship provided both increased confidence and tools that enabled the channelling of enthusiasms and achievable change. Previously there were ideas, but no know-how to put these ideas into action. Through the Fellowship, networks and relationships were built:

- With other Fellows, increasing individual awareness of what is possible
- With people from other fields (such as music and film) that allowed headway of the 'Alive Inside' activity

Organisational context

Although the acute trust is a challenged organisation, this nurse was encouraged to test out creative new approaches.

Barriers and hurdles

In their new post, historic roles and commissioning relationships make a whole trust corporate approach to dementia difficult. A next step will be to find a way of embedding a corporate strategic approach that draws on all the resources and expertise available across the trust.

Case Study 2

Leadership across organisational boundaries

Background and Rationale

This case study follows a GP in Kent who completed cohort 2 of the Dementia Fellowship.

It was chosen as a case study for a number of reasons:

- Here was a clear example of a GP undertaking change as a direct result of the Fellowship
- Their practice has a very high number of patients with dementia, so there was good scope for change
- Changes were initiated both within and outside their own practice

Ambition for the Fellowship

They already had a strong interest in dementia when applying for the Fellowship and their application noted that the practice had more than double the CCG average prevalence of people with dementia. They wanted to improve their knowledge and skills particularly in the assessment and management of dementia, understand and learn from good practice, and spread new knowledge within the surgery team.

Experience of the Fellowship

The Fellow "…thoroughly enjoyed…" the course: "It was fun, friendly and I learnt a lot". The multidisciplinary group was prized "*Everyone brought something to the table*" and they briefly kept in touch with one of the other Fellows whose work was drawn on to share good practice in care homes.

The leadership and change management elements were "*surprisingly helpful*". The interpersonal skills element of the course was appreciated. Learning from those with lived experienced as:

> *"The communication with dementia session…was really helpful and moving."*

They felt the speakers were "*pitched at the right level*."

Individual impact

This GP gained confidence from the Fellowship and this was critical to the ability to take learning from the programme, influence and make changes. They feel that their voice has been legitimised. For example, when unhappy with practice in care homes, it is challenged:

> *"It [the Fellowship] empowers you to say things aren't acceptable. I don't have a problem in raising concerns with a care home. Because you've got a sense there's a whole raft of people out there with similar concerns….*
>
> *Otherwise, as a GP you can be a bit isolated and don't realise others are having same concerns and that they also expect the same standards."*

The Fellow felt their clinical knowledge improved and learned more about dementia and the *landscape*: who is doing what. Their choice of change project (see below) spurred them on to learn more about nutritional tools, as well as about implementing change so this also increased their clinical knowledge.

This GP encourages the practice to think broadly about dementia, including implementing dementia aware initiatives and encouraging colleagues to ensure carers of people with dementia are on the Carers Register: *"I'm a nag."*

Wider impact

Coding exercise

The coding exercise energised the GP to tackle the issue of detection and diagnosis within the practice. But when the local CCG appeared resistant, they wrote a summary document, which helped persuade them to take this seriously. A GP colleague, who was interviewed for the evaluation, felt this was hugely beneficial and "*appealed to the logic of GPs*." The colleague also felt that the GP's encouragement to undertake dementia screening within the practice and increase diagnosis rates was really valuable:

> *"It was helpful for our practice income, but [more importantly] for addressing the issues involved. It made us all mindful."*

Change project

The Fellow undertook a change project as part of the course, using a problem-solving approach. Although this project aimed to improve nutrition in care homes, it had a wider effect as it changed practice in the care home to become more individualised and it resulted in a system change alerting primary care to weight changes in care home residents. This change was informed by the Fellow's professional view about how suboptimal responses by care home staff to patients twinned with knowledge of budget constraints resulted in a plan for change. An absence of specialist roles in the form of dieticians and gerontologist clinicians within community teams also drove the change project. Utilising project management skills, a phased approach to improving patient interactions was planned by the Fellow.

High engagement from the care home manager and training provider was an initial step, followed by active weight monitoring, with residents showing early signs of deterioration prioritised for care. These actions led to the use of and more wholesale and routine adoption of MUST scoring. The introduction of a monthly summary at the management reporting level embedded the practice from the front line upwards, leading to proactive patient support.

This system is still in place, despite care home closure and change of personnel. Practice has evolved to be joined by proactive diet supervision and a reduction in prescribed dietary supplements.

Challenges and thoughts

Challenges to the Fellowship

The Fellow enjoyed the course and had two interesting observations:

1. As a Fellow, they felt that the Fellowship could (and maybe should) have been a Long Term Conditions (LTC) Fellowship. They noted, for example, that a session on how to talk with people with dementia could equally apply to talking with people with a learning disability or autism. The skills are transferable. They questioned the notion of only being a dementia-friendly practice: *"What about a cognitive impairment friendly practice?"*
2. Linked to this first observation, the GP wondered about whether the money spent on the course might be better spent on a broader-based Fellowship, especially as specialist areas such as dementia can easily be replaced in policy and other trends by other LTCs.

Challenges

The biggest challenge for this GP was when the Care Quality Commission challenged the care home that they were working with. As a result there was a complete change in the care home leadership team, the home was closed to new residents for a period, and a new team was appointed. Although the initiated changes appeared to remain in place, the relationships that were built with the old team were therefore lost and there was a sense that instead of this being a shared piece of work, it was the GP's own project. It was clear when interviewing the new care home manager, that they did not have the same relationship with the GP as the previous manager.

Another challenge for the Fellow was that their own specialist interest in dementia, while still evident, has largely been overtaken by competing concerns: a lead role in diabetes instead of dementia.

Case Study 3

Leading holistic improvement in dementia care

Background and rationale for case study

> *"The big difference is early intervention (means) people have support and social input, people are not feeling abandoned. They rarely have to see a doctor."* (Fellow)

The Golden Ticket is an ambitious system-wide transformation project based within primary care. It is an increasingly high profile initiative, which the CCG is rolling out across a wider area, and it was influenced profoundly by experience gained through the Dementia Fellowship. In all, five Fellows have had a role in the development and delivery of the Golden Ticket, so this case study provides an insight into the collective impact that can be achieved by a group of Fellows working together on a shared initiative. From the evaluated cohorts, three fellows made up this team: a GP Dementia Lead; one clinical Chair of the CCG. Both were in cohort 1 together. A pharmacist, from cohort 2, joined them.

What is the Golden Ticket?

The Golden Ticket is a new approach to the management of dementia in the community, piloted by a GP practice in High Weald Havens CCG.

A service review showed that people living with dementia received a fragmented service, with built-in delays, and a medical model of support, despite people commonly facing social issues such as loneliness. Two GP Fellows, one of whom is the Clinical Chair of the CCG, as well as other CCG colleagues, secondary care, and non-statutory agencies, worked together to co-produce and pilot a new model. This took place in one locality to provide high quality early intervention and on going support to both the person with dementia and the carer or family. This includes service elements such as the provision of responsive, rapid support at critical times provided by primary, secondary and social care colleagues working together (the 'Blip' Clinic), community-based resources (such as a dementia café, which is located in the village pub) and reviews of medication.

Dementia guides from the third sector organisation Know Dementia act as the main point of contact for people with dementia and their carers. They provide emotional support and practical advice while also bringing in a range of agencies to support people when needed.

The Golden Ticket has been evaluated, and the feedback from people with dementia and their families has been *overwhelming*.

> *"[This person] would previously have been sectioned and put in a nursing home. We kept [them] at home." (GP)*

In addition, the Golden Ticket has reduced A&E attendances by 25%, and GP appointments by 20%, demonstrating that this approach not only improves quality of life, but also makes better use of resources.

The Impact of the Dementia Fellowship on the Golden Ticket

What was the impact of the Dementia Fellowship on the Fellows as individuals?

Self-understanding and personal skills

> *"The Fellowship gave (the leaders) confidence and support to develop their thinking in dementia."* (CCG Chief Officer)

The Dementia Fellowship increased Fellows' skills in caring for people with dementia and in designing better models of care, a point that was recognised by the CCG Chief Officer. All three Fellows spoke about the importance of caring for people with dementia in a holistic way, and of working to integrate care around the person with dementia. GPs were empowered by the knowledge and confidence they gained through the Fellowship. The lead pharmacist, also changed their practice to include all the various conditions and issues that might affect a person with dementia.

The contribution of other Fellows was also important in building knowledge and sharing learning. The range of different professionals and perspectives represented on the programme meant that there are lots of brains to pick.

Organisation and system context of change

"(The Fellowship) opens your mind and makes you make connections with others."

> *"I'm used to working on my own (as a GP). You have to know your role in the team, your part of the pathway and where it fits."* (Dementia Programme Fellow)

The range of multidisciplinary Fellows, together with content on pathways and service models, and contributions from a range of agencies, increased awareness of the wider network of community resources that GPs could draw upon. Through the programme, the GPs involved in developing the Golden Ticket, realised that they were not solely responsible for providing care and support to people with dementia, but formed part of a team.

> *"After (the programme) I became clear where my place was."* (Pharmacist)

A key impact for the pharmacist Fellow was not only understanding personal contributions to the pathway, but also having the skills and role recognised by GPs and other colleagues. For a paramedic, involvement in the Golden Ticket through the 'Blip' Clinic brought increased satisfaction in the role. The Golden Ticket allowed tracing of people with dementia and their carers along the whole pathway, building relationships and seeing improvements, a new experience for the GP.

The increased understanding of the system context achieved by Fellows also benefited the third sector, who were key partners in the Golden Ticket:

> *"It was the first time we felt our voice was being heard".* (Third sector representative)

Working with others

> *"We banged on doors until they opened."* (GP)

> *"We didn't focus on the money, it's about clinical care… We talked about how we could create something brilliant."* (GP)

The Golden Ticket was not a procured service, and the model was co-produced through an inclusive process that brought together local people, third sector organisations, local businesses, and other partners. It was also rooted in evidence collected on alternative models and their impact. Several interviewees commented on the persistence required to bring in key partners (the phrase 'banging on doors' was often repeated). Building a shared vision and clarifying what the new approach would look like therefore demanded a high level of influencing skills, which the Fellowship helped Fellows to refine.

Extending the Golden Ticket to the next wave of practices is also requiring a strategic approach to influence. As noted above, the strategy has been to focus primarily on improving quality of care.

Change management, service improvement and capacity building

> *"Nobody taught me how to do it until the Fellowship. It came at the right time*!" (GP)

Through the Fellowship's content on leadership and change management, Fellows refined their approach to leading change. Colleagues noted that their increased confidence in this area was evident.

Beliefs and values

> *"We asked, 'Tell me what it felt like to receive a diagnosis.'"* (GP)
>
> *"Sometimes you have to step back and ask the carer what the trigger for the behaviour is rather than giving (the person with dementia) a tablet."* (GP)
>
> *"It's not just looking at medicine, it's about living well with dementia."* (GP)

The Fellowship played a key role in strengthening the focus of Fellows on a person-centred, social model. This approach to looking at the whole person with dementia, their relationships and their quality of life underpinned the Golden Ticket initiative.

What was the impact of the Dementia Fellowship – leading change within a service?

Alongside the Golden Ticket pilot, the practice undertook a programme of work, led by the pharmacist fellow, to make the practice dementia aware. This programme of work included improving the environment, working to change staff attitudes, and delivering training. The Golden Ticket's pilot phase also included medication reviews for people with dementia. Through this process, about 25-30% of medications were stopped or changed for people with dementia, leading to savings and better outcomes for people.

Leading strategic and system change

> *"The Chair's clinical leadership developed (as a result of the Fellowship). As Chair and executive lead, the credibility … is significant. The Fellowship helped [them] grow into that. [They are] seen as a very influential system leader."* (CCG Chief Officer)

The Golden Ticket is an example of system change which has been implemented by Fellows, and which is rooted in the Dementia Fellowship emphasis on:

- Person-centred models of care
- Systems thinking
- Evidence-based approaches

Fellows reported that attending the programme increased their credibility with colleagues and strengthened their leadership skills to influence the CCG Board. CCG colleagues highlighted this visible increase in system leadership capability, as demonstrated in the quote above.

Critical success factors

Critical mass of Fellows

> *"The three together were a formidable force*." (CCG Chief Officer)
>
> *"Critical mass was important at the start and along the way."* (Interviewee)

The coming together of "*high quality individuals",* who had shared the experience of the Fellowship, created momentum for change. The Fellowship provided space to think differently about service design and development, as well as access to expertise and evidence. Strong project management also supported resilient leadership, based on relationships forged during the Fellowship.

CCG support

> *"Clinical commissioning and leadership have been key to this."* (Interviewee)

The CCG had the insight not only to recognise the problems with the existing service, but also to support clinical leaders to introduce a radically different approach, based on co-production and collaboration. The Golden Ticket has now become a good news story and source of pride for the CCG as national and international recognition grows. The impact on the CCG has been significant at a time when positive developments in the NHS can seem rare.

Challenges

The Golden Ticket's leadership team are undertaking a phased rollout of the model across the CCG, working with the Dementia Fellowship faculty team to partner and support their approach. As noted above, the aim is to work with GPs in other practices to persuade them of the value of this new way of working. Avoiding the tension between replicating the essential elements of the model whilst allowing a degree of local discretion. The next wave of practices will not have been through the Dementia Fellowship, so there is a concern that they will not fully understand the underpinning values of person-centred practice that have been so crucial to the Golden Ticket. The team is addressing this by delivering what they refer to as a "mini fellowship," in partnership with the Dementia Fellowship faculty team, to the next wave.

Appendix F: Case Study Data Sources

Case Study 1 - Data sources

Interviews:

Dementia Fellowship Participant	Phase 1, phase 2/3 interviews
Lead Nurse, Specialist Medicine, Acute Trust	Telephone Interview
Filmmaker	Telephone interview
Wishing Well musician	Telephone interview
Three dementia Matrons	Group interview

Observation:

Meeting of Dementia Implementation Group, Hospital setting, 24 January 2017

Document Review:

Dementia strategy, the Community NHS Trust, 2016

Application for DFP

Case Study 2 - Data sources

Interviews:

Telephone (Phase 1) interview

Face to face interview at the surgery (Phase 2/3)

Telephone interviews with a fellow GP in the practice (Phase 1)

Telephone interview with the nursing home manager (Phase 1)

Document Review:

Documents including application form and project report.

Case Study 3 - Data sources

Interviews:

Three DFP Fellows	Phase 1, 2/3 interviews
Chief Officer CCG	Telephone interview
Paramedic	Telephone interview
Buxted Practice	

Other:

Joint meeting with Health Foundation

Document review:

Golden Ticket Service Evaluation, Adam Gill, 2016

The Dementia Golden Ticket, An Emerging Model of Care, presentation at The King's Fund, February 2015

Fellowship applications, improvement plans