



Independent Evaluation of the

BSMS HEE KSS Dementia Fellowship Programme

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Summary

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The Dementia Fellowship Programme

Between 2014 and 2017, four cohorts of Dementia Fellows, totalling 102 healthcare professionals (GPs, nurses, hospital doctors, therapists, pharmacists and commissioners), took part in the Brighton and Sussex Medical School (BSMS) Dementia Fellowship Programme. The programme design was an innovative, modular course which specifically integrated clinical learning with leadership development and skills in service change and improvement. It was developed collaboratively with funding from Health Education England, Kent Surrey and Sussex (HEE KSS).

The programme was led by Professor Sube Banerjee, Director of the BSMS Centre for Dementia Studies, and by Breda Flaherty, Director of the BSMS M.Sc. Healthcare Leadership and Commissioning, working with a faculty of experienced development consultants.

Dementia represents a significant challenge for Kent Surrey and Sussex, 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. Dementia diagnosis rates, however, have been among the lowest of the English regions. Against this backdrop, dementia was identified as one of the priority programmes in HEE KSS's Skills Development Strategy 2013-2018.

This report presents the findings of an evaluation of the first three cohorts of the Fellowship carried out between June 2016 and April 2017 by Jane Carrier and Dr Edana Minghella. It considers the programme design, its impact on individual Fellows, and changes made to their clinical practice and the wider health system. It explores the interventions made to improve services to better meet the needs of people affected by dementia.

Programme design

The aim of the Dementia Fellowship Programme was to improve:

- **clinical knowledge** of dementia, and participants' sense of competence and confidence in understanding how to offer good quality dementia care
- **leadership and influencing ability**, to enable participants to lead positive change in their services for people living with dementia
- **change management and service improvement skills**, both to make practical local changes and to impact the wider health system

The challenge was to create a programme which could deliver individual development, clinical knowledge improvement, real service developments, and an impact on the wider system.

The composition of the programme team deliberately reflected the design challenge, incorporating: clinical expertise provided by leaders in the field; leadership development experts; whole systems and change management expertise; service and quality improvement skill; and grounded experience of designing, offering, and receiving dementia care services.

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 multi-disciplinary, 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.

Data collected during the evaluation was collated and analysed in relation to three identified dimensions of development:

- changes made in individuals' own professional practice
- changes made in specific services
- changes grounded in an ambition to affect a system of care

The Dementia Fellows: their experience overall

“For me, it was amazing. It changed me.” *(Nurse)*

- **84% of Fellows** reported improved self-development and professional practice through completing the Fellowship.
- **59% of Fellows** introduced changes in their own services, in every setting including primary care, hospitals, and a hospice. The result was tangible improvements in dementia care across Kent, Surrey and Sussex.

Selection onto the Fellowship programme involved application by interested individuals who were asked to demonstrate clear objectives for learning and aspirations for change related to the positions they held within the health service. All cohorts targeted a multidisciplinary group of clinicians, each cohort had a different focus including primary care, emergency care and general hospital care.

Seventy-five people completed the first three cohorts of the Dementia Fellowship, of whom the largest groups were GPs (43%), nurses (33%) and hospital doctors (13%). Other disciplines included: physiotherapists, occupational therapists, pharmacists and commissioners (11%). The Fellowship was restricted to those providing NHS-funded care, because of boundaries inherent in the HEE KSS funding remit. People working in the social care and voluntary sectors were therefore outside the scope of the scheme.

Sixty-nine percent of the eligible Dementia Fellows contributed

to the evaluation, describing the Fellowship overall in overwhelmingly positive terms.

- Through interviews and case studies, Dementia Fellows were identified 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 Fellows' 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).

Specific themes of the Fellows' experience included:

- Connecting with others and creating a robust network, in particular, learning from peers. This was regarded as a key strength, bringing together acute and primary and community care perspectives, enabling participants to understand each other's roles and to see across the whole pathway.
- The structure of the programme, particularly the residential element. Fellows liked the practical focus on service improvement, and the high quality and composition of both the delivery team and the external speakers, especially those who brought lived experience.
- Problems identified included difficulties in implementing change in their own organisational context. Some Fellows reported finding this frustrating, they perceived unresponsiveness in the system and faced challenges in managing change.

Dimension 1:

The impact of the Dementia Fellowship on individuals' own professional practice

“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 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)*

“The DF helps you think about how you perceive yourself. You suddenly realise – what I have to say is important.” *(Nurse)*

“It empowered me as a GP.... gave me a holistic view, not a medical model.” *(GP)*

“I’ve become evangelical about dementia.”
(GP/Commissioner)

“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.” *(GP Partner)*

“Bringing together clinical knowledge with leadership and improvement tools achieves epiphany moments.”
(Fellowship team member)

The evaluation questions first focussed on individual and professional practice, skills and values. Here, the aim of the programme was to motivate and enable Fellows to take up their authority differently, identifying themselves as leaders; the aim was to improve services by using enhanced skills and ideas as to what changes would improve life for people affected by dementia.

The main themes were:

- Increased confidence, better personal understanding of dementia and improved clinical practice through attending the Fellowship.
- A shift towards a more person-centred approach helped by the programme design, which emphasised the contribution of people with lived experience, and used experiential learning approaches.
- An enhanced understanding of the key role of carers.
- Better understanding amongst GPs that they were not solely responsible for all aspects of care but form part of a wider care system where other professionals and resources have a contribution.
- A development of understanding by Fellows that they had an important role, expertise and leadership potential.
- Refined skills in building relationships and influencing others, strengthened by the leadership and change management elements of the programme.

Dimension 2:

The impact of the Dementia Fellowship on leading change within services

“I can confidently say that I improved the care of dementia patients.” *(Nurse)*

“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.” *(Nurse)*

“I now spend an extra few minutes with patients (with dementia). I’m more aware of giving people extra time.” *(Hospital doctor)*

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

“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)*

“I thought, how do I go away and use what I have learnt?” *(GP)*

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

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

The second element of the evaluation focussed on leading change within their service. Of those Fellows interviewed, over half had introduced improvements in their own services, including primary care, hospitals, and a hospice.

The main themes included:

- Improvements to coding and diagnosis rates: in one Clinical Commissioning Group (CCG) area, diagnosis rates improved from 43% to 68%.
- Making primary care more accessible to people with dementia and their carers: 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.
- 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 the 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.
- Nurses in particular made moves to adopt person-centred approaches and exercises they had themselves experienced during the Fellowship. This learning reflected the 'dual task' envisaged in the programme design: role-modelling different approaches appropriate to working with whole systems; and immersing Fellows in the experiential learning derived from being a participant in such exercises.
- A range of examples explored further in the Evaluation includes: becoming Dementia friends individually, and in whole services/practices; establishing dementia – aware services; setting up a dementia café in primary care; supporting people with dementia to live well at home; improving the experience of carers of people living with dementia; improving admission to an ambulatory care unit; improving access to hospice care for people with dementia; improving resources, including information for carers; clinical tools such as pathway tools and proformas; a different approach to training, and the development of helpful resources, such as videos.



Dimension 3:

The impact of the Dementia Fellowship on leading strategic and system change

“(The Chair’s) clinical leadership developed (as a result of the Fellowship). As Chair and executive lead, the credibility she brings is significant. The Fellowship helped her grow into that. She’s seen as a very influential system leader.” *(CCG Chief Officer)*

“When talking to others about what needed to be done, I felt I knew what I was talking about.” *(GP)*

“The big difference for patients is early intervention, people have support and social input, people are not feeling abandoned. They rarely have to see a doctor.” *(CCG Lead)*

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

“(The Fellowship) opens your mind and makes you make connections with others.” *(GP)*

The third element of the evaluation focussed on how participants were leading on strategic and system change across boundaries. Examples and vignettes highlighted how learning from the Fellowship had been translated into action. In particular, Dementia Fellows implementing change beyond their own service generally had one or more of the following strategic aims:

- **Raising awareness and improving knowledge and skills:** examples included a GP taking the lead in raising awareness with colleagues and care home patients; taking a system-wide approach to raising awareness and improving experience; improving nutrition in care homes.
- **Improving detection and diagnosis:** examples included improving diagnosis rates in primary care and care homes, including CCG-wide initiatives.
- **Redesigning or improving pathways:** examples included an ambitious system-wide transformation project based within primary care, offering a socio-medical approach to dementia care in an increasingly high profile award-winning initiative, which the CCG is rolling out across a wider area; a GP Lead who had taken dementia awareness and dementia-friendly practice beyond his own GP practice and into the wider system of care, with his contribution covering much of the care pathway from A&E through to end of life care; working with primary and secondary care to improve pathways.
- **Reducing or avoiding hospital admissions:** examples included a community nurse working to reduce admission across two CCGs; three community nurse Dementia Fellows working together to reduce care home admissions.

Strategic changes often involved the challenges of integrating high levels of engagement and influencing skills, working across boundaries, modelling good practice and being fearless and less risk averse. Good examples of re-modelling patient pathways for people affected by dementia were identified.

Factors in implementing change

“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)

“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)

The fourth element of the evaluation focussed on contextual factors that influenced the ability of Fellows to implement change in practice, including:

- The work environment, and levels of autonomy associated with different professional roles: 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.
 - Culture change was a challenge for a number of Fellows trying to make change, especially across systems. For example, there was a 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’.
 - Sharing learning more systematically would have been valued by several Fellows; they commented that they would have valued some level of ongoing 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, largely through the initiative of one of them, and found this very supportive.
 - To measure impact, a few Fellows collected data to monitor whether their initiatives had made a difference. Mostly this was relatively accessible quantitative data, such as diagnosis rates, and could be used by Fellows to encourage colleagues to continue or take up the initiatives, (such as coding). The Evaluation found few examples of Fellows collecting a wider range of data. 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.
 - The Evaluation found that 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.
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Summary and Conclusions

The overall findings and outputs of the evaluation are summarised using the ‘Darzi evaluation principles of successful leadership programme design’ as an organising framework.

1 Clarity of purpose and aims

The Dementia Fellowship faculty were clear on the overall goals and purpose of the programme. The key question was how to design a learning programme that would improve participants’ potential to create better dementia care at 3 levels: (i) the individual’s professional practice (ii) specific services; and (iii) wider healthcare systems.

Additionally, there was an explicit aspiration to create a sustainable network of people with a shared commitment to improving care for people affected by 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.

2 Timing and synchronicity

For those Fellows who managed to achieve significant change the programme came at the right time, enabling a step change in thinking and the support to develop further; they were often aware that they needed

to do something to improve care for people with dementia, but before they joined the programme they were not clear what this should be. Timeliness, and synchronicity between the goals of the programme and individual or organisational priorities increased the chances of success.

3 Transformational change

Many Fellows experienced a ‘mind shift’ in their thinking and behaviour that enabled action to be taken with impact. For the majority of Fellows, the Fellowship resulted in transformational change at several levels. Many Dementia Fellows also described a revelatory shift at a personal level, but in different areas, including genuinely understanding the meaning of person-centred care for people with dementia; 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.

4 Ambitious but doable projects

The improvement projects were not pre-standardised or defined allowing a range of scope and scale.

5 Organisational context: committed sponsors and supportive organisational culture

This was variable and not all organisational contexts were conducive to providing encouragement and support. However, where this was in place, developments were significant. 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. 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 example, and the developments described in the lead dementia nurses’ case study, were underpinned by support from the host organisation.

6 High quality mentoring

A specific post-fellowship mentoring system was not in place. However, the support from the central faculty team was recognised as enabling Fellows to implement change.

Recommendations for others developing dementia leadership programmes

7 Multi-disciplinary participants

Many Fellows commented on the importance of the multidisciplinary mix of the cohorts. The multidisciplinary mix of the cohorts was important both in reflecting the system but also in relation to testing out new behaviours and attitudes across the system. Sharing experience and solving problems alongside other Fellows was a highly-valued aspect of the programme. 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.

8 On-going monitoring and adaptation

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

The learning from this programme has been significant and offers a wealth of ideas for people wishing to adopt similar approaches. In particular the following recommendations may be of use:

- Achieve the right mix of participants and consider finding ways of extending beyond the NHS to social care and the care home sector to support a system-wide response.
- Ensure that the delivery team reflects a similar diversity of skills, professional background and personal experience.
- Surface and address issues of assumed seniority and hierarchy within the group from the first day.
- Build into the programme design:
 - opportunities to build networks and encourage shared problem solving;
 - combine enhancing clinical knowledge with skills development and attitude and behavioural change;
 - learn from those features of the Dementia Fellowship programme design which were highly valued including residential blocks with time for reflection and implementation between.
- Bring in lived experience of dementia as a central theme. This programme cannot be designed or run without the contribution of people whose lives are affected by dementia.
- Provide ongoing support to maintain momentum and focus – action learning groups, coaching, communities of practice, mentors and champions.
- Create opportunities through enhanced network development and the necessary skills to feed learning from the Dementia Fellowship upwards and outwards to influence service development and policy debate.
- Consider how best to target the programme to maximise impact – through selection processes, multi-disciplinarity, and cross system responses.

To read the full report, appendices and case studies, please visit www.bsms.ac.uk/research/neuroscience/cds/resources.aspx or www.networks.nhs.uk/nhs-networks/bsms-dementia-fellowship

For further information about the Dementia Fellowship, please contact Breda Flaherty (b.flaherty2@brighton.ac.uk) or Vikki Pearce (v.pearce@bsms.ac.uk)

The Centre for Dementia Studies (CDS) works to improve the quality of life of people with dementia and their family carers by improving the quality of treatment and care they receive.

The CDS is a joint venture between BSMS and Sussex Partnership NHS Foundation Trust. Its programme of work in applied health research, education and policy in dementia is designed to improve the quality of life of people with the condition.

Good-quality dementia care requires multi-disciplinary and inter-agency working, with patients and carers at the core.

The CDS works in collaboration with a number of partners, including the Universities of Brighton and Sussex, patient and carer groups, primary care providers, Health Education England working across Kent, Surrey and Sussex (HEE KSS), clinical commissioning groups (CCGs), acute NHS trusts, local authority social service departments, private care providers, wider regional and national universities, and other organisations.

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