Slaying the Demon
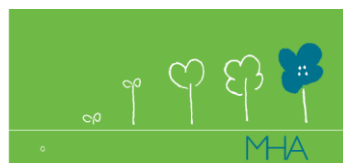
The Dementia Challenge: Progress and Achievements

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Acknowledgements

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Foreword

There can be no doubt that the delivery of high quality care and support for patients and families living with dementia is a major challenge for health and social care services. As a nation we are living longer and we are seeing more people living with co-morbidities including dementia. Whilst our effort must remain on improving diagnostic and therapeutic interventions to treat and manage dementia, we must also be focused on supporting patients, families and carers who are living and coping with dementia on a daily basis. They need co-ordinated support and high quality services now, not the promise of improvements in the future. It was within this context that the NHS South Strategic Health Authority invested and commissioned work to advance innovation and identification of best practice across provider services in the South of England. We recognised that there was much to be proud of, but our challenge was to highlight best practice and innovation and share that with wider audiences and encourage adoption of excellence.

This important report provides a valuable window on the work that is currently being developed across the South of England and in a wide range of services. The projects and programmes are extremely diverse, and are at different stages of development. We are continuing to learn about what works and what doesn't. Many of the projects are multi-agency and all are actively engaged in partnership working across disciplines and - importantly - are working closely with patients and carers. The work is not easy, and unfortunately structural re-organisations and reform of the NHS and Social Care, and continuing funding challenges, have caused some delays in progressing the projects. However, the commissioners and authors of the report believe it is of vital importance to share the findings thus far, whilst recognising that many of the projects are still on-going and will continue to develop. Our aim is simple – we want to encourage dialogue and sharing in a field of research and practice that is engaging with one of the greatest health and social care challenges of our time. We believe that further investment and research is clearly needed but we also recognise that by adopting best practice *now* across all organisations we can also help those patients, families and carers who need high quality services and support today and tomorrow. We must continue to invest, research and advance our knowledge and understanding in the dementia field, but as we do we must apply our findings to our daily practice and not ignore the small interventions that can improve the lives of so many on a daily basis. This report is designed to support practitioners, commissioners, delivery agents, patients and carers by shining a light on the best practice and innovations we have found today. Please engage with it, share it, and adopt the best.

Professor Steven West DL: Vice-Chancellor UWE, Bristol

Chair of the West of England Academic Health Science Centre
Chair of South of England SHA Patient Care Standards Committee

Executive Summary

Slaying the Demon[1]: The Dementia Challenge Fund:
Progress and Achievements

1. The Dementia Challenge was launched by the Prime Minister in March 2012 with the objective of "delivering major improvements in dementia care and research by 2015." Progress reports published in May 2013 and 2014 highlighted the momentum the challenge had generated, and the step-change in response. Nonetheless, the transformation is far from complete, and a continued national focus will be required to maintain and develop responses to the biggest health challenge facing the country.

2. In responding to the Dementia Challenge, **NHS South of England established its own Dementia Challenge Fund** (DCF) of £9 m - allocated across almost 70 projects - to drive local improvements and to identify and implement practical solutions to the problems faced by people living with dementia. Projects addressed one or more of 8 key themes:

   - Dementia friendly communities.

   - Living well at home.

   - Better care in hospitals.

   - Improving diagnosis.

   - End of Life care.

   - Reducing anti-psychotic prescribing.

   - Better support for carers.

   - Living well in care homes.

3. NHS South of England commissioned an independent review of the programme. Many of the projects are 'work in progress' and it would be inappropriate and premature to talk about evaluation of final outcomes. Nonetheless, it is clear that the programme has generated a great deal of activity, considerable innovation and real achievements.

4. The review adopted an approach that combined breadth and depth. Contact was attempted with all the projects through an on-line questionnaire; further in-depth work was then undertaken through follow up with a sample of more than 30% of the projects. A very high completion rate was obtained to the questionnaire and returns were received from more than 91% of projects. The questionnaire returns indicated that projects were addressing multiple themes. Better support for carers, living well at home, and promoting a dementia friendly community were the themes most likely to be identified.

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[1] Sir Terry Pratchett was diagnosed with Alzheimer's in 2007. He has said: *"The first step is to talk openly about dementia because it's a fact, well enshrined in folklore, that if we are to kill the demon then first we have to say its name. Once we have recognised the demon, without secrecy or shame, we can find its weaknesses. Regrettably one of the best swords for killing demons like this is made of gold – lots and lots of gold. These days we call it funding."* Foreword in *Dementia: Out of the shadows*, Alzheimer's Society (2008).

Outcomes and Achievements

5.   At the time the questionnaire was completed most projects were clear that it was far too soon to judge what had been achieved. Many projects had experienced delays in getting underway, and at the time of the survey (Autumn 2013) were still in very early days of operation. Nonetheless, on the basis of progress to-date, there was a sense that projects were on-track and were achieving about the same or more than had been expected at the outset. Almost all projects indicated that evaluation processes were in place, although some of this was monitoring rather than evaluation as such.   However, a range of approaches were in use including satisfaction surveys; pre and post-intervention questionnaires; qualitative feedback; and KPIs.

6.   It was not possible in practical or logistical terms within the parameters of the review to have further detailed contact with all projects. An approach was developed to allow further exploration of experience with a sample of 21 projects. The fieldwork (undertaken in Spring 2014) involved visits to four locations (and discussions with 47 individuals across these sites), alongside semi-structured telephone interviews with the remaining 17 projects (involving 31 interviews).

7.   We analysed the 21 projects using the classification of the 8 major themes of the DCF (although recognising that in practice projects often ranged across several of these). We identified a number of recurrent cross-cutting conclusions and messages including:

- Cultural change

- Start-up and sustainability challenges

- Organisational reform and disruption

- Importance of strong and inspirational leadership

- Importance of wide public engagement

- Empowerment through new skills and knowledge.

8.   It was apparent that in many projects, and especially those developing **Dementia Friendly Communities,** multiple stakeholders were involved and activity was usually much wider than would be anticipated in conventional health care initiatives. Interviewees typically spoke glowingly about the flourishing community enthusiasm and engagement that had been achieved.

9.   DCF projects were funded for 12 months and most projects were acutely aware of the constraints this entailed and were careful to avoid establishing reliance on particular appointments that could not be sustained.

10.   **Improving care for people with dementia in residential homes and in hospitals** was a focus of several of the projects, and included attention to both the physical environment, and improving the skills and understanding of care staff. **Empowering staff has enabled greater continuity of care to be achieved, and improved personalisation to address individual needs.** This has included reduced reliance on anti-psychotic drugs to manage the behaviour of people with dementia, and greater confidence of care staff to understand and meet complex needs.

11.   The NHS South of England Dementia Challenge set out to stimulate and encourage CCGs working with local authorities, the voluntary and independent sectors and other local partners, together with people with lived experience "to identify and implement practical

solutions to the problems faced by people living with dementia." **The cultural change that is required to establish genuinely inclusive dementia friendly communities is profound.** This has implications not only for the health and social care economy, but for a breadth and depth of vision that embraces all aspects of society. This can include, for example, the built environment; public transport; high street shops and services; and schools and colleges. The experience of the projects has underlined both the challenges that this entails, but also the potential for transformation when the agenda is embraced across agencies and organisations. **Successful innovation typically requires partnership between many different agencies**, as this project lead observed:

"We can't do it on our own. This is a cross-partnership commitment, and we need to move from the bio-medical model, which doesn't work in this arena, to a psychosocial model (...) It's all down to the passion and commitment of a whole series of people – all I've done is to galvanise them and pull them together."

12. A key part of the cultural change is often around how an organisation views dementia, and moving this from being a separate specialism to a dimension which crosses all aspects of care and support, since people with dementia are likely to use a range of services.

13. Projects that were concerned with living well in care homes, with reduced prescribing, and with End of Life care also illustrated the cultural change that was particularly associated with **empowering care staff through better understanding of dementia**, and equipping them to continue to support people in place rather than to refer them to inappropriate or unnecessary hospital care. Such empowerment reflected the wider cultural shift within organisations and how they view and understand dementia. Increased job satisfaction was identified frequently, with the added potential benefit of reduced staff turnover, particularly in the care home sector.

14. **The achievements of projects have often far surpassed expectations.** An intergenerational project found children and young people having completely different attitudes to dementia as a result of a short intervention and engagement with care home residents. In other projects too, interviewees commented frequently on their surprise at the level of interest and engagement of other organisations and agencies across the community. Active engagement with people who live with dementia and with their families and carers, and with the wider community have been distinguishing features of successful projects, particularly in tackling stigma and misunderstandings of dementia.

15. On the national stage, the Prime Minister's Challenge on Dementia set the target of achieving 20 cities, towns and villages signed up to be Dementia Friendly Communities by 2015. In fact, the second year progress report on the Dementia Challenge highlighted the achievement that 50 communities had already signed up to become dementia friendly, and the target for 2015 had been revised to 75.[2] There is considerable interest and enthusiasm for developing local dementia strategies throughout the country, and there is much in the DCF with the potential to inspire and stimulate wider developments.

16. Embedding cultural change will be vital if the achievements of the DCF are to be sustained and built upon. Many project leads and coordinators commented on their concern to avoid establishing practices and models that would be reliant on appointments that would end with the DCF funding. In many instances, as we have reported, projects were being brought within core budgets and being developed further by organisations that recognised their value.

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[2] http://dementiachallenge.dh.gov.uk/2014/05/07/champion-groups-letter/

Start-up and Sustainability

17.   The DCF was launched at a time of considerable turbulence and change in the structure of the NHS. The disappearance of Strategic Health Authorities and Primary Care Trusts in April 2013 brought massive changes of personnel and local organisational arrangements. The impact of these on networks and on continuity was substantial, and the challenges of responding to the new environment were identified repeatedly.

18.   Start-up difficulties were reported by many of the projects, and typically these were associated with frustrated efforts to recruit and appoint project staff. Sometimes this had been avoided by people incorporating the project within their work remit, or by organising internal secondments. With projects that were funded for only 12 months, any delays in getting underway impacted significantly on achievements within that time frame. Many projects argued that it would have made more sense to have a longer lead time, and it was too soon to judge achievements in many cases, and evaluation data was incomplete or still in development. Nonetheless, it was also evident that even within a short time scale projects *had* succeeded in delivering tangible outcomes and in opening local debates that were likely to continue.

19.   People who had been involved in putting together the original bids for DCF projects had sometimes moved to other posts and responsibilities by the time funding was awarded and projects needed to commence. For the review team this brought its own significant challenges in tracking and tracing projects, and for the projects themselves there was an inevitable hiatus.

20.   Gathering evidence on achievement and outcomes was ongoing for most projects. This reflected the slow start that many had experienced in getting projects off the ground. It was also the case that projects needed to adjust their success criteria as they evolved, particularly when other achievements were identified. Because so many of the projects are concerned with developing approaches that require cultural change and new ways of thinking and operating, their achievements are not readily measured by KPIs or similar. Such projects were gathering qualitative evidence and were able to point to significant shifts in ways of working and approaches to dementia. Clearly, other projects *do* lend themselves more readily to quantitative assessment and measurement (for example, reducing the prescribing of anti-psychotic medication to patients with dementia).

21.   Most projects were developing plans and making a business case for their continued existence, and in some instances CCGs and partners had committed to taking the work forward. Securing ongoing support for work (beyond another 12 months for example) will continue to be challenging in a climate of economic restraint. However, in many instances projects had developed a momentum and had expanded the partners they were working with; had equipped a wide range of people with skills and knowledge, all of which created a likelihood of sustainability that was not reliant on the continued presence of a project manager or coordinator – other people had taken ownership.

Conclusions

22.   Considering the DCF programme overall, we conclude that much has been achieved and there have been many positive benefits that were not anticipated at the outset. We recognise that this is work in progress and it is vital for cultural change and new ways of working and understanding to be embedded in organisations if the achievements are to be sustained and built upon. It is important that the findings and experience of the projects (and of the PM's Challenge on Dementia) are widely disseminated and shared, and this report is a contribution to facilitating the debate that needs to continue to transform the approach to dementia and to improve the lives of people with dementia and of their carers.

23. As with much innovation, the success and momentum of many of the DCF projects owed a great deal to the **passion, drive, vision and persistence of project leaders**. Such enthusiasm was infectious and inspirational, and was tangible, as this EOL care practitioner observed:

"We love what we do and (...) we will finish knowing that we have made a difference. Most people – it doesn't matter what you do, like to feel that you've made a positive difference, and we know that we have."

24. The review did not set out to compare the additional value of the DCF in supporting a programme of development compared to other areas that were not adopting a similar strategic approach. In the light of the PM's challenge on dementia, there is arguably greater awareness of dementia matters throughout the NHS in England. Some of the initiatives supported under the DCF might have developed without the additional funding, but others would definitely not have done. Certainly many of the projects were believed both to have been possible because of the DCF, but also to have established a foundation for future development, as this project leader concerned with dementia awareness training in hospitals observed:

"The fund has allowed us to begin transforming care for those living with dementia; this is just the beginning."

25. We believe therefore that the DCF generated considerable added value by investing in the strategic development of services and initiatives to better support people with dementia and their families. If a similar approach were to be followed again we would recommend particular attention be paid to the following:

   ➢ Developing a new initiative during a period of major organisational change introduces various risks and delays which require mitigation if programmes are to be delivered appropriately.

   ➢ Ensure that governance arrangements are fit for purpose and consider the balance between accountability requirements and project support.

   ➢ Recognise that sometimes 'less is more' and relatively modest amounts of additional funding can make a considerable difference (such as to cultural change and the built environment), while changing the model of care (reducing prescribing and retraining care and health staff with alternative skills, for example) is likely to demand considerably more investment.

   ➢ Recognise that project start-up typically takes longer than expected particularly when staff need to be recruited, and factor this into timescales.

   ➢ Encourage projects to network and share experience, both by making use of a dedicated website, and by facilitating regional and local events, enabling people to pool experience and share challenges and solutions as they emerge.

   ➢ Disseminate findings widely, recognising that the experience of developing projects can be as valuable as the outcomes delivered. Projects that may not have appeared to achieve as much as others may nonetheless have learnt a great deal through the process and be well placed for developing new approaches in the longer term.

   ➢ Avoid adopting a hierarchical approach to outcomes and recognise that 'softer' qualitative measures and quality of life dimensions are important, and as valid as harder financial measures and value for money indicators.

   ➢ Recognise that the dementia challenge is not a strategic task that can be achieved within a year or two, but that the cultural awareness and shift in ways of understanding the needs of people living with dementia will need continued attention and regular refreshing if it is to achieve maximum potential.

Slaying the Demon: The Dementia Challenge
Progress and achievements

1 Introduction

1.1 The Dementia Challenge was launched by the Prime Minister in March 2012, with the central objective of 'delivering major improvements in dementia care and research by 2015.'[1] Speaking at the launch event, David Cameron observed:

> *"One of the greatest challenges of our time is what I'd call the quiet crisis, one that steals lives and tears at the hearts of families, but that relative to its impact is hardly acknowledged.*
>
> *We've got to treat this like the national crisis it is. We need an all-out fight-back against this disease; one that cuts across society."*

1.2 The PM's Challenge on Dementia built upon the National Dementia Strategy established in 2009, and focused on three key areas:

- Driving improvements in health and care

- Creating dementia friendly communities

- Better research.[2]

1.3 The document contained 14 'key commitments' (see Box 1 below) and an extended list of actions. The overall ambition with dementia was stated succinctly:

> *"Through research, we will in time find a cure. But until we do, every effort must and will be made to improve the lives of people with dementia and their families and carers."[3]*

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[1] Department of Health (2012), *Prime Minister's challenge on dementia. Delivering major improvements in dementia care and research by 2015.*

[2] Department of Health (2012), Op Cit. P.5.

[3] Department of Health (2012), Op Cit, P.19.

Box 1: The Prime Minister's Challenge on Dementia: Key commitments

DRIVING IMPROVEMENTS IN HEALTH AND CARE

1. **Increased diagnosis rates through regular checks for over-65s.** We will ensure that GPs and other health professionals will make patients aged 65 and older aware of memory clinics and refer those in need of assessment. From April 2013, there will be a quantified ambition for diagnosis rates across the country, underpinned by robust and affordable local plans.

2. **Financial rewards for hospitals offering quality dementia care** From April 2012, £54m will be available through the Dementia Commissioning for Quality and Innovation (CQUIN) to hospitals offering dementia risk assessments to all over-75s admitted to their care. From April 2013, this will be extended to the quality of dementia care delivered. Also for April 2013, access to all CQUIN rewards will be dependent on delivering support for carers in line with the National Institute for Health and Clinical Excellence (NICE)/Social Care Institute for Clinical Excellence (SCIE) guidelines.

3. **An Innovation Challenge Prize of £1m** NHS staff can win up to £1m for innovative ideas for transforming dementia care.

4. **A Dementia Care and Support Compact signed by leading care home and home care providers** Ten leading organisations have set out their commitment to deliver high-quality relationship-based care and support for people with dementia, and to engage and involve the wider community in this work.

5. **Promoting local information on dementia services** We will promote the information offer pioneered by NHS South West, which will be launched on 28 March 2012 and rolled out across the south by the end of 2012. From April 2013, similar information will be available in all other parts of the country. We will also be setting out in the Care and Support White Paper further steps to ensure that all people receiving care and support get better information to support their care choices.

CREATING DEMENTIA FRIENDLY COMMUNITIES THAT UNDERSTAND HOW TO HELP

6. **Dementia-friendly communities across the country** By 2015, up to 20 cities, towns and villages will have signed up to become more dementia-friendly.

7. **Support from leading businesses for the PM's Challenge on Dementia** Leading national organisations have already pledged to look at how they and others can play a part in creating a more dementia friendly society and raising awareness of dementia.

8. **Awareness-raising campaign** From autumn 2012, we will invest in a nationwide campaign to raise awareness of dementia, to be sustained to 2015. This will build on lessons learned from previous campaigns and will inform future investment.

9. **A major event over the summer, bringing together UK leaders from industry, academia and the public sector**, to take forward the PM's Challenge on Dementia.

BETTER RESEARCH

10. **More than doubling overall funding for dementia research to over £66m by 2015** The combined value of the National Institute for Health Research (NIHR), Medical Research Council (MRC) and Economic and Social Research Council (ESRC) funding for research into dementia will increase from £26.6m in 2009/10 to an estimated £66.3m in 2014/15.

11. **Major investment in brain scanning.** MRC will make a major additional investment in dementia research using the BioBank. MRC anticipates piloting the brain scanning of a subset of this national cohort, with a view to rolling out to 50,000–100,000 participants.

12. **£13m funding for social science research on dementia (NIHR/ESRC).**

13. **£36m funding over 5 years for a new NIHR dementia translational research collaboration to pull discoveries into real benefits for patients. Four new NIHR biomedical research units in dementia and biomedical research centres which include dementia-themed research will share their considerable resources and world-leading expertise to improve treatment and care.**

14. **Participation in high-quality research** Offering people the opportunity to participate in research will be one of the conditions for accreditation of memory services.

1.4   As the Challenge document highlighted, tackling dementia has implications which go beyond health and social care, and indeed beyond government and "is a challenge to the whole of society." Each of the three themes has an associated 'champions group' bringing together leading organisations and groups to support delivery and take the work forward and deliver major improvements by 2015. The first annual progress report was published on 15 May 2013, and a further update was provided in a letter from the Champion Groups to the PM on 7 May 2014. The 2013 report observed that the Challenge on Dementia

"..has created a new momentum in health and social care, research and across society as a whole to do more to help and support people with dementia, their carers and families." [4]

1.5   The report identified some important shared themes emerging across the three Champion Groups including:

- Increased public and professional awareness and understanding.

- A drive towards making integrated care and support the norm.

1.6   The updated report in May 2014 observed:

"We are clear that dementia will still remain the biggest health challenge facing the country today and in the future – with still much more to do. It is our view that the timescale and parameters set out in the Prime Minister's Challenge document have driven a step-change in responding to dementia, not a completed transformation. A continued national focus and drive will still be necessary beyond the life time of the Prime Minister's Challenge on Dementia." [5]

NHS South of England: Dementia Challenge Fund

1.7   In responding to the Dementia Challenge, NHS South of England[6] established a Dementia Challenge Fund of £9m to drive improvements.   The SHA Board asked one of its Non-Executive Directors, Terry Butler CBE, to chair a staff group to steer the Programme and recommend projects for funding. These were then signed off by the Board. Guidance for

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[4] Department of Health (2013), *The Prime Minister's Challenge on dementia. Delivering major improvements in dementia care and research by 2015. Annual report of progress.* P.4.

[5] http://dementiachallenge.dh.gov.uk/2014/05/07/champion-groups-letter/ P.9.

[6] NHS South of England was a cluster Strategic Health Authority which brought together three former SHAs (NHS South Central; NHS South East Coast, and NHS South West). It existed between October 2011 and March 2013, when it was succeeded by a new NHS Commissioning Board and local clinical commissioning groups.

applicants was published in June 2012 inviting expressions of interest. Initial submissions were received from 165 applicants, and 129 full applications were received. Applications were considered by sub-regional panels and scored against agreed criteria, and funding was agreed for 69 projects in November 2012 "to identify and implement practical solutions to the problems faced by people living with dementia." The projects addressed one or more of eight key themes:

- Dementia friendly communities

- Living well at home.

- Better care in hospitals

- Improving diagnosis

- End of life care

- Reducing anti-psychotic prescribing

- Better support for carers

- Living well in care homes

Review of the programme

1.8   The SHA Board recognised that it would be important to review the progress of all the projects within the programme and to do so beyond the closure of the SHA and Primary Care Trusts in March 2013. Terry Butler agreed to oversee this and another SHA Non Executive Member, Professor Steve West, Vice Chancellor of the University of the West of England, offered the resources of the University to host the Review.

1.9   Terry Butler invited Melanie Henwood[7], a highly experienced independent health and social care analyst and researcher, with particular expertise in personalisation, care and support for older people and adults with disabilities and their carers, to assist him and to write this report. Prof Steve West then appointed Dr Katherine Pollard, Senior Research Fellow as the third member of the Review Team, on behalf of the University, given her extensive experience in managing and conducting qualitative research and evaluation. The work was commissioned on 1st June 2013, and in many respects the review was taking place at a relatively early stage of implementation and in real time. It cannot be regarded as a final

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[7] www.melaniehenwood.com

'evaluation' given the ongoing nature of the projects, but it *is* intended to provide an overview of progress and to highlight emerging good practice and innovation, as well as to identify any matters of concern.

1.10   The overarching Terms of Reference agreed for the review were as follows:

- *To draw out the learning from the initiatives in order to promote good practice and innovation in delivering better outcomes and value for money for people living with dementia and their carers.*

- *To sample the projects to:*
- explore how people have used the dementia money;
- identify best practice and learning for a wide audience;
- shine a light on dementia and the work needed to meet the challenge;
- highlight best practice for the future.

1.11   The Review Team developed an approach to the review that enabled maximum value to be obtained and findings from across the programme to be captured. Thus contact was attempted with all the projects by means of an on-line questionnaire. The analysis of returns was then used to inform a second stage of in-depth fieldwork with a sample of projects. Our approach and methodology are described in Appendix 2. We begin, however, by presenting the findings from the questionnaire.

2   The DCF projects: snapshot and overview

2.1   An on-line questionnaire was developed to capture some standard information and activity data across the Dementia Challenge Fund (DCF) projects. The questionnaire was tested and went live on 9th September 2013 with a completion deadline of 27th September. Reminder emails were sent at intervals to non-responders and deadlines extended for those unable to meet the completion requirement. It became apparent that some projects are 'phantoms' in as much as they were listed as part of the successful DCF programme, but in practice do not appear to exist or to have been funded. Some projects that appeared as separate items in the database had merged in practice, for example where there were a number of projects that operate under a county-wide banner.[1] This meant that some projects appeared to be unresponsive to our communications but in reality were picked up by other respondents providing an overview of a cluster of projects.

2.2   Returns were collated from 63 projects out of a potential list of 69 (which may in fact be 68 or fewer). This represented an exceptionally high response rate of 91%, and the few returns that were outstanding were chased on multiple occasions without success. The responses were variable in quality and comprehensiveness but they provided an excellent foundation for understanding and analysing the programme as a whole.

2.3   Before examining the findings in detail it is worth making some introductory observations. It is striking that many of the projects were slow to get started, and a small minority had still not got underway at the time of our survey. Projects often require a longer lead time than is assumed and problems with recruitment or unplanned absences can introduce significant implementation difficulties. Delays in getting started inevitably mean that for many projects it is premature to expect clear evidence of outcomes and achievement. The second observation is that the organisational churn that has been experienced as a result of NHS structural reform has had a profound impact on the projects. There have been changes of lead personnel which have added to delays, and there remains confusion or uncertainty about governance and reporting approaches that are or should be in place for the projects since April 2013. However, most project leads were extremely cooperative in complying with our requests for information and many were enthusiastic about their projects and eager to share their experiences.

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[1]   Further information on individual projects and their findings is available via the website: http://dementiapartnerships.com/tag/dcf/

Overview of the projects

2.4   The graphs and figures below present some key basic data about the projects and their operation.

Figure 2.1: DCF Funding allocation
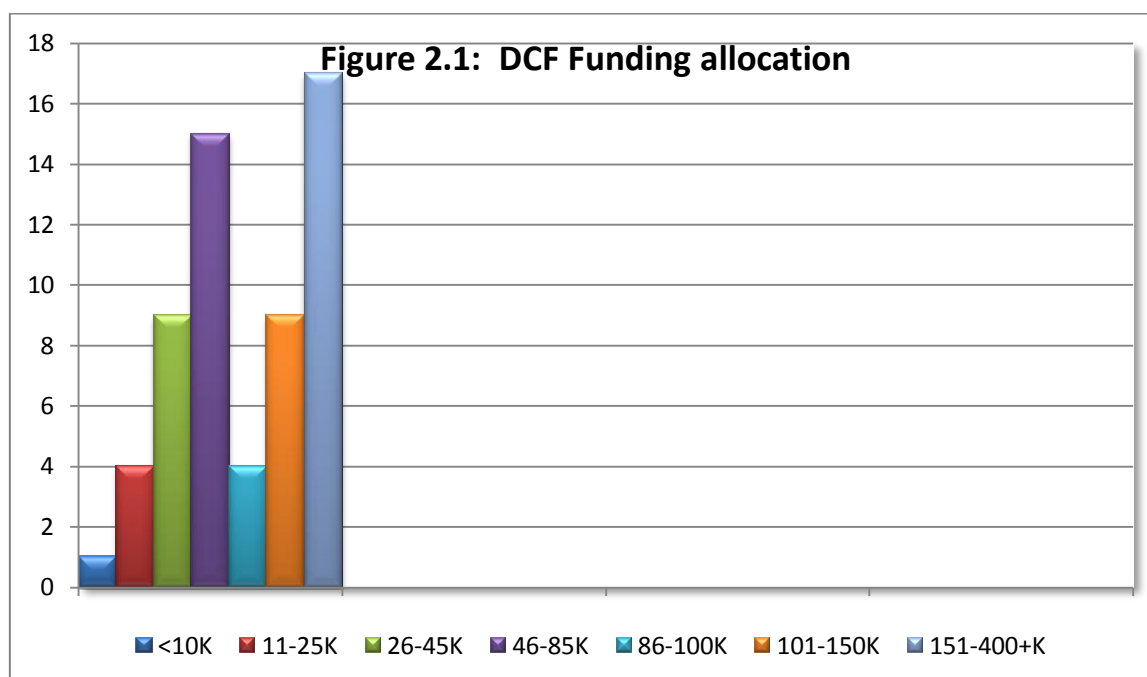
2.5   Figure 2.1 summarises the distribution of funding across the projects; a small number of projects had funding of £25K or less, with a larger clustering between £46,000-85,000, and the largest number of responding projects funded in excess of £150K. The smallest funding allocated to a project was £8,000 to support a training course for carers around understanding dementia. The largest allocations (above £400K) were for £445,744 (Innovative care across the community and care home in Cornwall); £415,000 (supporting dementia friendly communities in Somerset); reducing the prescription of anti-psychotic drugs in Kent and Medway (£405,000). In all cases, applications were only funded with "an expectation" that there would be at least an element of local resourcing, either in cash or in kind. Some of the larger projects were typically multi-dimensional or umbrellas for a number of separate but linked initiatives.

On track?

2.6   Figure 2.2 demonstrates the spread of projects' experience in getting underway. Several respondents distinguished between beginning work and getting funding allocated. In some projects different components of the project had to start at different times largely because of issues with staff recruitment. As the graph indicates, the dates when projects got underway were extremely variable, but most had not begun work until well into 2013, and at the time of our survey (August/September 2013) a small minority had yet to start.

Figure 2.2: Project commencement
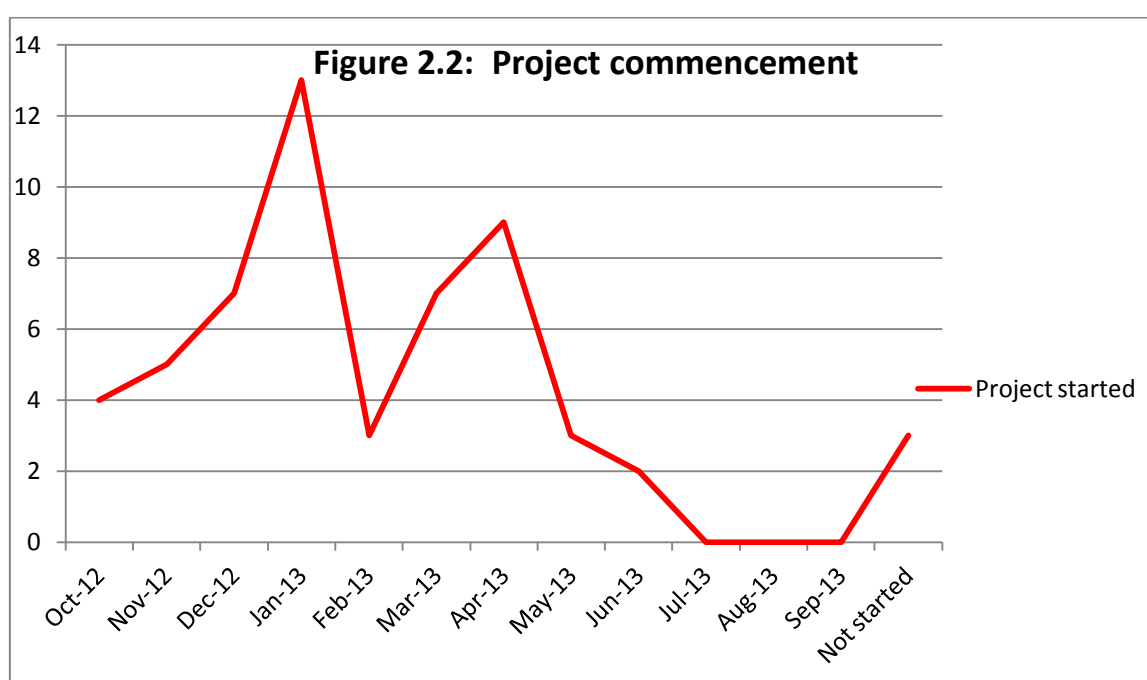
2.7   Questionnaire respondents offered a range of comments and further information about their projects. Where projects had been delayed in getting underway, respondents highlighted the difficulties in setting up a new project and the 'time lag' that is often experienced in bringing plans to fruition. Some of the following comments underline the problems encountered:

"Been some delay in recruiting people. Access to surgeries and venues has been difficult, but they now have four courses set up." (C017, 'Understanding Dementia – a training course for carers')

"[project has] yet to start due to difficulties recruiting to the post." (C045, 'Training for domiciliary care providers in Berkshire.')

"The project is at the planning stage." (C051, 'Dementia friendly ward environment at Frimley Park Hospital')

2.8   All of the projects that responded appeared to be continuing to operate. A small number of respondents (9) acknowledged that there were risks to their project delivery. Where a project is reliant on recruiting specific personnel, managing timescales can be especially challenging, for example:

"We were unable to recruit for the secondment post for the medication review pharmacist role so an existing member of staff has taken this on in addition to her existing workload." (C025, 'Medicines optimisation in East Berkshire care homes')

Some projects had decided to reconsider their approach because of recruitment issues:

"Due to issues with recruiting to the Admiral Nursing Service (because of the one year fixed term) we have taken the opportunity to re-model and expand the service to include a greater range of professionals. We have also committed to extending the project to 3 years." (E002, 'Sussex Admiral Nurses')

And:

"The focus of the bid is being reviewed as the initial bid was to recruit 3 mental health nurses to work in primary care. But after two recruitment attempts only one has been recruited. The current consideration is piloting the voluntary sector to support patients and carers to prevent crisis." (E027, 'Early diagnosis and post-diagnostic support in West Kent')

2.9   Other projects similarly reported HR-related difficulties, such as W008 ('End of life care planning for patients with dementia in Dorset') around their inability to backfill nursing time to free up capacity:

"The nurses are still managing to do the project but spending less time than anticipated on the project. We have only managed to recruit one person to do advance care planning."

2.10   One project attributed delays to structural changes impacting on the hospital where they had planned to focus their work:

"Due to the imminent move to the new hospital, the bedbase for people with dementia has not been finalised. We have plans for the areas that may be chosen but cannot complete until this base is definitively identified. This is expected by end of September/beginning October." (W021, 'Delivering a stimulating hospital environment in Bristol')

2.11   Two projects that were both operating in Kent and Medway highlighted the problems they experienced following NHS reorganisation:

"An element of funding to support the projects is still being held in legacy funds, but there is currently no guarantee that this money will transfer to CCGs. This has been highlighted to the CCGs and the potential shortfall in funding identified." (E038, 'Improving community care and reducing anti-psychotic prescribing', and E040 'Improving the patient experience in acute hospital settings in Kent and Medway.')

2.12   Some other projects indicated that there had previously been risks to delivery but that these had been addressed. For example, C009 ('Dementia friendly communities') remarked that risks were no longer significant "now that we have been able to recruit to the second half of the project." However, this position had only been filled in the previous month and it was recognised that part of the project was "well behind" as a consequence.

2.13   In addition to the snapshot of progress that we wanted to obtain from the questionnaire, we also planned to analyse quarterly reports that the projects were required to submit as part of the governance arrangements for the programme. However, we were unable to collate a comprehensive set of such reports and there were major gaps in the information available. In particular, almost all the reports relating to South Central projects (those prefixed with 'C') were not available to us. It is understood that these were 'archived' and despite attempts to locate them and cooperation from local personnel, their whereabouts remained unknown. Other report sets were also incomplete, and very few reports later than March 2013 could be obtained.

2.14   It became apparent that the reporting arrangements for projects since April 2013 were somewhat unclear. Indeed, several projects submitted their latest reports directly to the review team and assumed this was now the correct reporting process. Whether other projects were continuing to prepare or submit reports anywhere was not clear. As one respondent observed "this appears to have fallen off the radar since the birth of the CCG and reorganisation etc."

Focus and approach

2.15   The DCF programme was designed to address a range of themes and broad objectives that had been targeted as 'priority areas for consideration'.[2]   Eight such topics were identified and projects were asked through the questionnaire to indicate which of these they believed they were addressing (since many were addressing more than one theme).   The distribution of responses is summarised in Figure 2.3.

Figure 2.3: Thematic focus
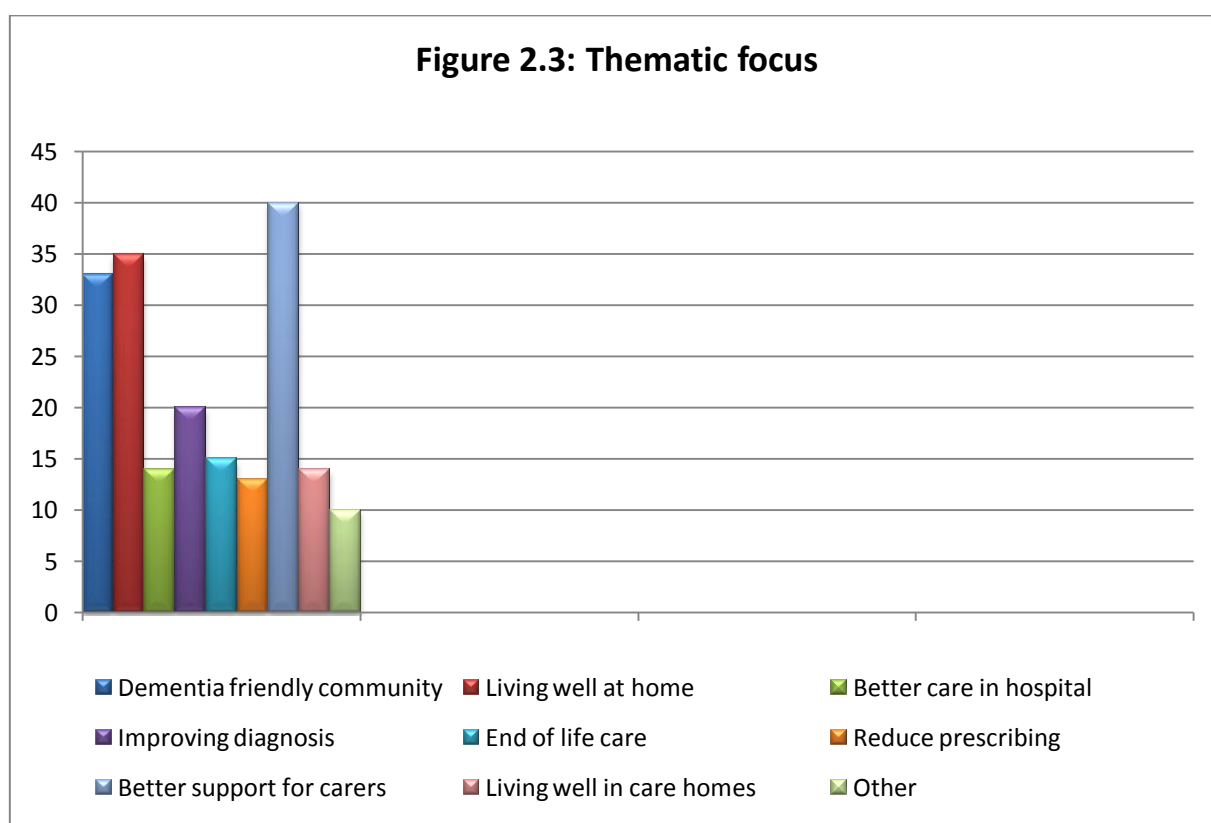
2.16   As the chart demonstrates, the great majority of respondents to this question (40 out of 60) selected 'Better support for carers' as an objective of their project, and this was the highest scoring theme, closely followed by 'Living well at home' (35), and promoting a 'Dementia friendly community' (33). A small number of projects (10) also indicated a further theme for their work (the 'other' category) which were:

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[2] NHS South of England (2012), *NHS South of England Dementia Challenge 2012: Guidance for applicants.*

- Better inclusion for people with dementia (W023)

- Better use of resources and independent living in the community (W028)

- Dementia friendly care homes (W029)

- Inter-generational work (C009)

- Improving access to dementia support, and reducing hospital stays (C056)

- Listening to needs of people with dementia and their carers through story telling (E007)

- Reduce carers' stress, and improve health, wellbeing and knowledge (C017)

- Improving access to dementia support and information, reducing hospital stays (C056)

- Listening to the needs of people with dementia and their carers, through a variety of storytelling mediums (E007)

- Reduce carer stress; improve carers' health, wellbeing and knowledge (C016).

2.17   The Bristol dementia inclusion programme (W023) regarded its particular approach as distinctive from a conventional 'Dementia-friendly communities model', as they explained:

"[this movement] tends to perpetuate the traditional view of dementia but campaigns for increased 'friendliness' and support whilst continuing to frame people in terms of worsening symptoms and inevitable need for services."

2.18   By contrast, the Bristol dementia inclusion programme was explicitly based around principles of social inclusion:

"Working to develop a social inclusion approach to dementia that recognizes it as an illness that occurs in a wider social and relational context. Encouraging the citizenship of people with dementia where they are valued and continue to have things to offer."

2.19   W028 ('Keeping track of dementia in Torbay') was distinctive for focusing on demonstrating the effectiveness of Global Positioning System (GPS) tracking devices for people with dementia at risk of getting lost. The project was addressing the experience of service users and their carers, and exploring the impact on the use of health and social care services, particularly whether the use of GPS can delay admission to residential care.

2.20   The Torbay and South Devon dementia care home learning community (W029) was aiming to improve the quality of life for people with dementia living in care homes, and in so doing, to reduce the need for acute hospital admissions, reduce anti-psychotic prescribing and improve staff retention.

2.21   The emphasis on inter-generational work by C009 was a theme that featured in a small number of projects. C009 (Dementia friendly community) was deliberately involving young people as volunteers in supporting people with dementia.

2.22   Better support for carers was identified as the *sole focus* of only one project (C017 'Understanding dementia – training course for carers'), but featured repeatedly as an additional theme across other projects that recognised the wider benefits of their approach for carers. For example, projects focusing on promoting Dementia friendly communities, Living well at home, or End of Life Care were also likely to recognise that this would be of benefit to carers, and similarly this was true of those projects concerned primarily with improving diagnosis and reducing the prescription of anti-psychotic drugs.

Evaluation and Outcomes

2.23   Projects were asked about their approach to evaluation and how they would know if they were successful. Almost all the responding projects (57 out of 63, or 90%) stated they were undertaking some evaluation of their approach. A small number (7, or just 11%) indicated that they were carrying out economic analysis of the value of the project. We turn now to explore these responses in further detail.

2.24   The half dozen projects that indicated they are *not* currently conducting any evaluation need to be seen in context. Some of the projects have nothing to evaluate at present owing to delays with getting started, for example:

"Projects are not yet at the stage where anyone has benefited as the directories are still in production." (C023, 'East Berkshire dementia services directory')

"Not applicable as project is yet to start." (C045, 'Training for domiciliary care providers in Berkshire')

"The project has not yet started due to issues with recruiting into posts." (E002, 'Sussex Admiral Nurses')

2.25   Other projects which had still to begin interventions nonetheless indicated that they were evaluating the project (i.e. they intended to do so). One respondent did not believe that it would be possible to evaluate the impact of the project because far larger changes were taking place:

"The changes to the environment are dwarfed by the other major staffing and environment changes from the new hospital building and it will be impossible to compare to previous stage." (W021, 'Delivering a stimulating hospital environment in Bristol')

Evaluation Methods

2.26   Projects varied enormously in the detail they provided about the methods they were adopting for evaluation.   Some projects had conflated monitoring and evaluation; one project, for example cited the quarterly project monitoring reports as their evaluation method. The applications that projects submitted to the DCF required them to identify 'quantifiable benefits' that would be achieved for people with dementia and their carers, and to state 'how and when' these would be measured.   A number of projects indicated that their methodology was largely around 'feedback' received, but others cited more specific approaches including:

- Pre and post-training questionnaire for staff.
- Satisfaction surveys for people with dementia and their carers.
- Simple data collection based on diaries, care plans and goal attainment scores.
- Mood scoring, patient feedback.
- Health and wellbeing questionnaires.
- Audit of KPIs (including reduced use of antipsychotic medication and reduced admissions to secondary health care).
- Monitoring diagnosis rates, admission rates, health check rates etc.
- Social return on Investment (SROI).

2.27   Several projects described the anticipated outcomes of their project rather than providing an account of their methods.   For example, "*staff will feel more confident in managing people with dementia; the use of volunteers has increased and staff have a sense of satisfaction.*"

2.28   Many projects indicated that while they would be evaluating the project, it was too soon to offer anything substantive.   For example, W023 ('Bristol as a dementia friendly city') observed:

"We will be happy to share evaluation and any other reports as they emerge.   However, after only 8 months, the expectation of such documents is premature."

2.29   Seven projects (11% of respondents) indicated that they had commissioned external evaluation from academic institutions. The findings from such evaluations will not be available in the immediate future and certainly not during the course of our review. Two other projects (E006 and E007) referred to work being undertaken by Professor Judith Holton of Mount Allison University, New Brunswick, Canada "looking at 3 projects in the UK who have or are using social movement to make a change". However, this did not seem to have been commissioned by the projects.

2.30   It is important to acknowledge that the range and type of projects funded under the DCF programme means that outcomes and evaluation will be similarly diverse. Projects that are focused on promoting a dementia-friendly community, for example, are likely to employ qualitative evaluation tools. Qualitative dimensions are also likely to be a feature of a number of other thematic priorities (such as better support for carers, living well at home etc), while some of the other themes are likely to be more suited to quantifiable data (such as reduced prescribing or reduced residential placements). What is important is that appropriate measures are developed and employed. Some projects indicated that because they were working on improving dementia awareness in the community, and although it is "likely" that many people have benefited "It's not able to be quantified." Appropriate evaluation techniques should, however, be able to demonstrate whether the project has had an impact. Another respondent commented:

"The programme is beginning to take hold, but to be able to count numbers of people who have benefited is not yet possible as the kind of work involved is developmental and will take time to show tangible benefits. We are concerned about the expectation of measurement of social inclusion work in such a short timeframe." (W023, 'Bristol as a dementia-friendly city')

2.31   The projects including economic analysis of their impact did not generally provide further detail about their approach, but most were monitoring quantifiable data. As one responded observed:

"This is very early days for this kind of work. Economic benefits are hard to measure in the short term. Some of the methodology from SROI (Social Return on Investment) might be able to help us with this later on."

Another observed that they had not undertaken economic analysis but "we will try to evaluate this as part of our overall evaluation."

Achievements

2.32   In addition to project-specific objectives and evaluation of their achievement, projects were asked to indicate if they believed they were achieving significant benefits against a number of dimensions. Figure 2.4 summarises the responses.

Figure 2.4: Significant Achievements

Significant achievements

- Improved staff understanding
- Organisational cultural change
- Improved public understanding
- New training materials
- Better quality care
- Innovative models of care
- Improved quality of life for people with dementia
- Improved quality of life for carers
- Increased confidence to support
- Improved and earlier diagnosis
- Improved community support
- Improved partnership
- Other

2.33   The highest scoring areas of achievement were identified by respondents as:

- Improved quality of life for people with dementia (40).
- Improved staff understanding and awareness of dementia (39).
- Improved quality of life for carers of people with dementia (38).

2.34   As the chart demonstrates, several dimensions clustered closely together and were rated by at least 25 (45%) respondents as significant achievements. In descending order these were:

- Development of new training materials (33)
- Improved community based support (31)
- Improved wider public understanding and awareness of dementia (30)
- Improved partnership working between health and social care (29)
- Organisational cultural change (26)
- Better quality care (25)

2.35   The three remaining dimensions were rated as follows:

- Introduced or spread innovative models of care (22)
- Increased confidence to support people in the community (21)
- Improved and earlier diagnosis (16)

2.36   Finally, 6 respondents also identified 'other' dimensions including improved end of life care, improved voluntary support for people with dementia, and improved choice of services and support for people with dementia and their families and carers.

2.37   Respondents were asked whether the projects had achieved (or were achieving) more or less than had been hoped. Figure 2.5 summarises responses.
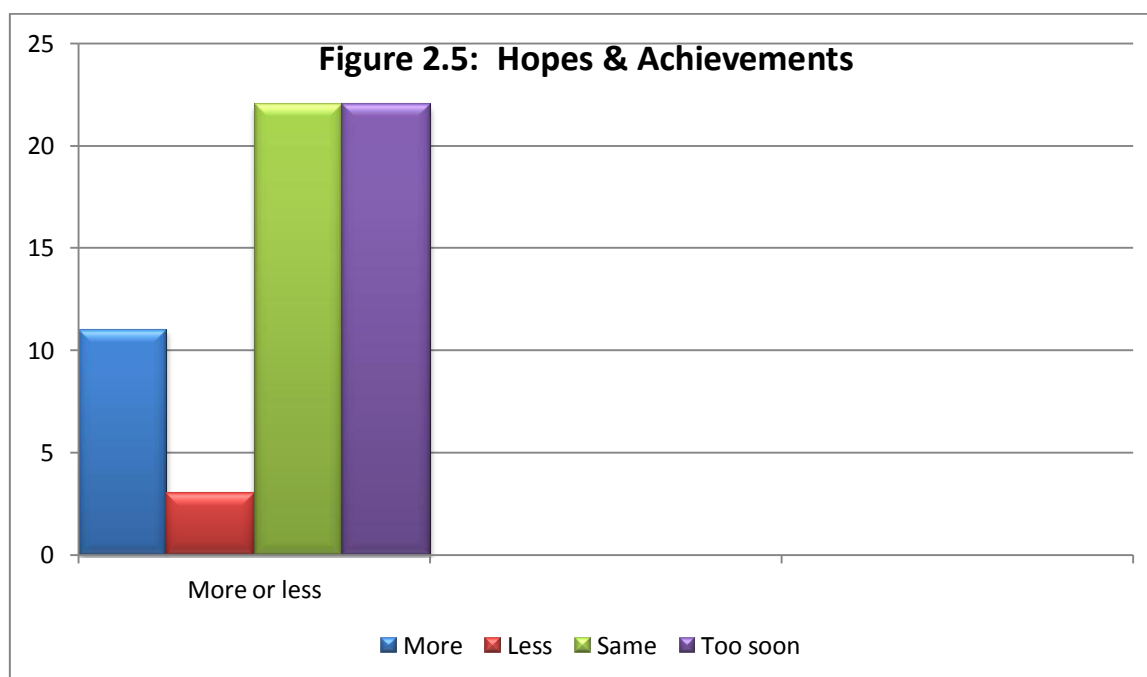
2.38   It is striking that the most common response (from 38% of respondents) was that it is simply too soon to judge what has been or is being achieved; the same proportion indicated that they thought the project was achieving about the same as they expected. However, it is also clear that very few respondents (just 5% or 3 out of 58) indicated that the projects were achieving *less* than hoped. The fact that many respondents believed it is too soon to know what is being achieved is entirely consistent with the delays that many projects

reported in getting underway. Some projects were cautious in making judgements about their achievements at this stage, as these comments indicate:

"The project is only half way through delivery, the evaluation of outcomes will not be completed until later in the year. We do know the numbers of people that have taken part in many of the elements of our project but we can't evidence the difference it has made at this stage." (W004, 'Dementia friendly Plymouth')

"1st quarterly carer survey very encouraging, length of stay falling but variable by month, so still work in progress." (W016, 'Integrating hospital and community care pathways in Bath')

2.39 Furthermore, where projects were operating across a wide geographical area and involved different trusts, progress may be at different stages, as this project respondent observed:

"The project is being implemented across four acute trusts in Kent and Medway which are at slightly different stages of implementation." (E040, 'Improving dementia care in hospitals across Kent and Medway')

"Different communities will all progress at different rates and in different directions to suit the needs and aspirations of that community – our role is to facilitate that progress." (E037, 'Dementia friendly communities in Kent')

2.40 Some projects acknowledged that it is difficult to interpret evidence or to determine cause and effect, for example:

"In some ways the team has exceeded expectations. Feedback from homes and partner agencies is very positive and other homes are seeking to become involved. However, the rate of change has varied from home to home; some homes are more receptive and open to new ideas than others. We have no clear data to evidence a reduction in unplanned admissions to hospital – this will probably take longer to show. Training has been delivered but there is not always a clear correlation to changed practice." (C007, 'West Berkshire Care Home In-Reach team')

2.41 The projects had clearly evolved as they have gone along and many had needed to adapt their focus or methods depending on experience. Similarly, projects may be achieving outcomes on some dimensions but not on others. A project working on providing individualised care using reminiscence environments commented:

"The portable IT based life story system (mylife software) in conjunction with The Sunflower Lounge has achieved the projected outcomes when we looked at changes in patients'

mood although it is too soon to judge regarding the reduction in the use of antipsychotic medication and reduction in the number of falls." (C024, 'Reminiscence and individualised care therapies in Windsor)

2.42   Projects that were particularly focused on achieving cultural change and winning hearts and minds emphasised that such changes take time to be realised, for example:

"Project started slowly and as it involves cultural change, this takes time to implement." (W024, 'Enhanced, more responsive and preventative community based care in Gloucestershire')

And

"This is inevitably an experiment, changing people's attitudes and their behaviour is challenging. A lot will depend on what is sustained afterwards." (W034, 'Dementia Action Alliance for Pathway and Cribbs Causeway')

2.43   Some respondents were clear that they were putting in place the necessary foundation to secure continued expansion, for example:

"The purpose of this project is to serve as a facilitator and enabler. When this funding ends the necessary framework will have been put in place to enable the baton to be passed to the community of Hampshire to take this work forward for themselves. In order to achieve sustainability we need to build strong foundations." (C046, 'Dementia friendly communities in Hampshire')

2.44   Around one in five of the responding projects indicated that achievements were above their expectations, and many were clearly enthusiastic about their experiences:

"Excellent to see how personal 'hands on' training can make a difference in care homes – who really value this training." (C011, 'Achieving excellence in end of life for people with dementia in North Hampshire')

"The project has been a great example of how to break away from the traditional top-down PCT-led decision making and give real ownership and creativity to patients and GP practices." (C026, 'Enhancing the early diagnosis of dementia across East Berkshire')

"The project continues to surpass expectations, largely due to the good work of the Dementia Alliance who, under the steer of commissioners, are proactively driving the project aims and ambitions to success." (C056, 'Living well with dementia')

Sustainability

2.45   When evaluating applications and deciding which would be funded, projects were judged against a number of criteria including how improvements would be sustained over time. We asked projects therefore if and how their project would be continuing beyond the period of funding. Of the 57 respondents who answered this question, all but 4 (7%) indicated that the project would be continuing (although some qualified their response and indicated that this was an aspiration rather than necessarily a firm commitment). Two other projects were unsure if the project would continue (C016 and C017). The 4 who said they did not expect the project to have a continued existence were:

- C009 ('Dementia friendly communities')
- C025 ('Medicines optimisation in East Berkshire care homes')
- E023 ('Specialist link nurses in Surrey Downs')
- W020 ('Volunteering and dementia in Bristol')

2.46   However, comments offered by these respondents indicated that the situation was not necessarily fixed. The respondent for C009, for example, commented:

"We will be looking to persuade the council to continue the project in some form. We also plan to explore other funding streams."

E023 similarly explained:

"CCG is to be provided with business case to continue funding as it has been so well received by GPs and patients and the local mental health trust."

While C017 remarked:

"Not sure about funding."

And W020 also observed that the funding position was "unknown as yet."

2.47   None of those who were unsure about further funding or did not think the project would continue indicated that this was because it was believed the project offered poor value, had not delivered outcomes, or was redundant. The issue was simply about securing funding at a time of extreme pressure on resources. This awareness was also apparent among some of those who hoped or believed that their project *would* continue as this respondent explained:

"Yes, probably, in some form, too early to judge. Steering Group are however keen to learn from this 'experiment' and see what can be maintained in the longer term, whether specifically for people with dementia or in terms of social inclusion more generally. The CCG leads on the commissioning of dementia services but this work fits well with the Council's work on community capacity building and reducing isolation and loneliness." (W034, 'Dementia Action Alliance for Patchway and Cribbs Causeway')

2.48   One way in which projects might be sustainable is if they are scalable and offer a foundation on which to build. Project respondents were also asked for their reflections on scope and scale. Of the 58 respondents who addressed this question, 43 (74%) believed the model *was* scalable, and many offered extensive comments on how this could be approached. For some, this would begin with expanding the geographical area; for example, an approach currently being undertaken in West Berkshire could be extended:

"The approach could be replicated in other areas. Once fully evaluated we hope to replicate in Berks East." (C004, 'Cognitive stimulation therapy training in West Berkshire')

"If the training is successful the model could be rolled out throughout the community and throughout other LA areas." (C042, 'Dementia awareness in the community')

And

"Move the pilot to project status across a larger area." (C033, 'Collaborative dementia care in Oxfordshire')

2.49   One of the projects promoting the dementia friendly community described how success was likely to continue to build:

"We are rolling out the library health work across all 17 of our libraries and there will be a permanent post of 'health librarian' created to take the work forward. We anticipate that more schools will take up the dementia work that has been demonstrated to be so successful in our pilot school." (W004, 'Dementia friendly Plymouth')

2.50   Another project (using GPS devices to track people with dementia) believed that the work provided a foundation not only for local expansion but nationally:

"The project will enable this type of service to be delivered at scale by offering it to both state-funded people as well as self-funders. The pathway once established and proven is expected to be scalable on a local to national basis." (W028, 'Keeping track of dementia in Torbay')

2.51   As one respondent commented with enthusiasm "good practice is contagious!" (C015, 'Diverse communities engaged with dementia in North Hampshire'); further evidence that this is true was provided in this response:

"Another area in Somerset has approached us to help support them with becoming a Dementia Friendly Community." (W017, 'Dementia Friendly Community in Somerset')

Some of those who did not think the model was scalable commented that they were *already* applying it on a county-wide or authority-wide basis.

2.52   In some situations the next phase of expansion was already underway. This respondent described how a six month initiative to extend the model had begun in September 2013:

"A 6 month development opportunity for a new GP to lead the full implementation of the project across all CCG member practices, with a pathway redesign on how to expand the memory clinic services has been defined." (C026, 'Enhancing the early diagnosis of dementia across East Berkshire')

2.53   Others indicated that they would be focusing on the evaluation of their projects in order to develop a business case for further expansion, or that successful approaches would become part of normal mainstream activity where possible. Evidence of effectiveness is clearly key to enabling scaling up to take place, as this respondent commented:

"Evaluation data being used to open conversations with commissioners across neighbouring areas." (W020, 'Volunteering and dementia in Bristol')

2.54   Some respondents also highlighted the legacy that they were trying to create through their project, for example:

"We are trying to build a strong base of thinking to the programme that will outlive it. The work is seen as providing a series of starting points and in most cases, we are encouraging change rather than the purchase of new services/interventions. Every piece of work is designed to be able to continue autonomously beyond the life of the 2 year programme." (W023, 'Bristol as a dementia friendly city')

2.55   Despite the DCF wishing to encourage improvements to be sustained over time "and reduce the 17 year gap that it takes proven best practice in health and care to become

widely adopted"[3], it is clear that there remain risks of gains being lost at the end of project funding. Some projects alluded to this volatility, for example:

"Unclear – they need more money as they are a small charity and I am not sure the CCG can support it long term." (C014, 'Diverse communities engaged with dementia in North Hampshire')

2.56   A project that had difficulties in recruiting to a project post concluded that this constrained future extension or expansion:

"We were unable to recruit for the secondment post for the medication review pharmacist role so an existing member of staff has taken this on in addition to her existing workload (...) do not have the resources to continue." (C025, 'Medicines optimisation in East Berkshire care homes')

2.57   Another project similarly commented on circumstances that had apparently frustrated the ability to take forward the project. The project was focusing on delivering a stimulating hospital environment but was doing so at a time when the hospital was moving to a new site:

"New hospital is PFI build and we will be unable to transfer good practice and environment changes across to it." (W021, 'Delivering a stimulating hospital environment in Bristol')

Dissemination: sharing and spreading learning

2.58   Capturing and sharing the learning from the DCF initiative was a requirement for all projects from the outset. Sharing experience (good and bad) is central to spreading good practice and enabling innovation to become widely adopted and mainstreamed. Respondents were asked about their approach to dissemination; of the 58 respondents who replied, 54 (more than 93%) indicated they were taking steps to share experience and disseminate findings. The four who were not (W021; E027; E024; E002) included the following comments illustrating both optimism and pessimism:

"Not applicable at the moment but we will in due course. The project has not yet got underway because of recruitment issues but we have taken this opportunity to re-model

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[3] NHS South of England (2012), Op Cit, P.2.

and extend the scope of the project to 3 years which we believe will deliver greater benefits." (E002, 'Sussex Admiral Nurses')

"Have not had the experience of change yet and all we could share is frustration at not being able to get started at present." (W021, 'Delivering a stimulating hospital environment in Bristol')

"I envisage this will happen but it is too early to say." (E027, 'Early diagnosis and post-diagnosis support in West Kent)

2.59   Respondents who are disseminating their experiences identified a number of methods and processes they are adopting including:

- Newsletters and leaflets
- Journal articles
- Websites/webinairs
- Social media
- Local media and local public events
- Library information and online directories
- Presentations to local partners
- Presentations at local and national conferences
- Updates to commissioners
- Presentation to Trust Board
- Sharing on a whole systems group basis
- Sharing with county-wide Dementia Partnership Board and local dementia implementation groups
- Regional events and commissioning forums
- Local stakeholder events

2.60   As many respondents recognised, dissemination is an ongoing activity rather than something that only occurs at the end of the project, for example:

"Although the project is not yet halfway through so too early to trumpet success, we have a media strategy that attempts to tell the story of the new innovations we have adopted." (W016, 'Integrating hospital and community care pathways in Bath')

2.61   Dissemination of experience is not only about promoting success and spreading innovation; there is much to be learned from the processes that people have gone through; the difficulties and barriers they have encountered, and the solutions they have developed.

This was not something that we explored in depth with the questionnaire but was something that we examined in greater detail in the next stage of the research. As the analysis presented above has highlighted, many of the projects experienced difficulties in getting off the ground, or in delivering results within the expected timeframe; further understanding of some of the variables impacting on this experience is likely to be invaluable in enabling practice to be replicated and developed without repeating the same difficulties.

Conclusions

2.62   This section of the report has presented the key findings to emerge from analysis of on-line questionnaire returns from the DCF projects. The questionnaire included both closed and open questions, and the summary analysis has examined both quantitative and qualitative responses. The picture that emerges is one painted with a relatively broad brush but with some elements of fine detail. It is not possible to provide a detailed account of every project, but the data enabled us to create an overview of the DCF that has a number of distinctive features. Some of the key findings are highlighted below:

- Around 78% of projects responded to the survey by our initial deadline and following reminders the response rate rose to more than 90%.
- Most projects were helpful and cooperative although there had often been changes of key personnel and tracking down the right contacts was extremely time-consuming.
- The DCF provided significant funding ranging from £8,000 to almost £450,000, and with most projects receiving more than £150,000.
- Many projects experienced difficulties in getting off the ground; most did not get started until 2013 and a small minority were still not fully operational by the autumn.
- Considerable lead time is needed to become operational and many projects appeared to have underestimated this.
- Particular difficulties were encountered with recruiting or seconding staff for projects.
- Despite some difficulties, very few projects believed there were ongoing risks to their delivery.
- Governance and reporting arrangements for the projects were a matter of some confusion, particularly since April 2013, and it was unclear what requirements existed for ongoing quarterly reporting. The location of copies of some reports prior to April was unknown despite intensive investigation.

- The DCF projects addressed a wide range of priority areas and many projects focused on more than one thematic area. The theme cited most frequently by projects was 'support for carers' (although this was the sole focus of only one project), closely followed by 'living well at home' and promoting 'dementia friendly communities.'

- Almost all respondents indicated that they were evaluating their project but only a small proportion (11%) were undertaking any economic evaluation.

- Evaluation methods were various and some projects described monitoring activity as evaluation.

- A range of methodologies were in use including satisfaction surveys, feedback and pre and post intervention questionnaires, alongside monitoring of KPIs.

- For most projects it was too early to expect evidence of outcomes.

- Some 11% of responding projects had commissioned external academic evaluations of their work.

- Two thirds of projects indicated that improved staff understanding and awareness of dementia, and improved quality of life for people with dementia were major areas of achievement.

- Almost 40% of respondents believed it was too soon to judge what had been achieved, but on the basis of experience so far only 5% believed that their project was delivering less than hoped.

- Most respondents were cautious about over-interpreting early experience and wanted to await full evaluation results before claiming success.

- 93% of respondents expected their project to continue beyond the initial funding period, and others were seeking to make a business case for continuation in due course.

- 74% of respondents believed that their project could be scaled up for wider adoption and roll out, and some of this was already in evidence.

- More than 93% of respondents were disseminating their findings and experience, and this took a number of different forms. Most were using a range of approaches as work progressed, while some were awaiting final evaluation and conclusions before considering sharing experience more widely.

3 Fieldwork Findings

3.1 Building on the overview findings from the questionnaire returns we developed a strategy for further exploration of progress and achievement in a sample of the projects. It was not possible in logistical terms to visit or examine all the projects in greater depth, but the approach we adopted allowed us to have more detailed engagement with 21 projects (just over 30% of the total). As we demonstrate in Appendix 2, the selection criteria we developed enabled us to achieve a good spread of projects in terms of geography; thematic focus; and scope and scale.

3.2 We undertook site visits to four locations, which involved interviews and discussions with 47 individuals (including project leads; Commissioning managers; clinical nurse specialists; Alzheimer's Society Dementia Support Workers; Age UK leads; Support Workers; people with dementia and their carers). Interviews with the remaining 17 projects were conducted by telephone using a semi-structured interview schedule. Interviews took place with all project leads and supplementary interviews were arranged to follow up information with other key individuals as required. In total this involved interviews with 31 respondents. We wish to place on record our appreciation of the cooperation we met with across the projects, and we are grateful for the time that people willingly gave to discuss their projects and share their experiences. We met with enormous enthusiasm; respondents were almost universally keen to highlight the achievements of their projects, and equally eager to learn from other DCF projects. Respondents were refreshingly candid and non-defensive in sharing their reflections and experience. We had limited direct contact with people with dementia and their carers who were involved in the projects, although we made use of opportunities to meet people where possible. By and large our knowledge and understanding of outcomes for people living with dementia and for their carers has therefore been obtained by reliance on secondary sources such as reported feedback and qualitative monitoring and evaluation.

3.3 As we have described in Section 2, the DCF projects are highly diverse in many important dimensions, not least in terms of the eight themes and broad objectives. Although there are some overlaps between the themes, and most projects were addressing multiple aims, it is apparent that projects cannot simply be compared with one another given their varying objectives. The Table below provides summary information about the projects examined in greater depth, and groups them by main themes. As we have commented previously, most projects were addressing more than one theme, so the taxonomy below adopts the major focus of each for ease of classification. In the analysis which follows, we draw out the richness and multi-dimensional nature of many of the projects.

Table 3.1: Thematic Grouping of Fieldwork Projects

Dementia Friendly Communities	Living Well at Home	Better Care in Hospital	Living Well in Care Homes	End of Life Care	Improving Diagnosis	Reducing Anti-psychotic Prescribing	Better Support for Carers
W005: Integrated and inclusive communities across Cornwall.	W024: Enhanced, more responsive and Preventative Community based care in Gloucestershire.	W016: Integrating Hospital and Community Care Pathways in Bath.	C007: West Berkshire Care Home In-Reach Team.	W011: Innovative Care Across the Community and Care Home in Cornwall.	C026: Enhancing the Early Diagnosis of Dementia Across East Berkshire.	E038: Improving Community Care and Reducing Anti-psychotic Prescribing in Kent and Medway.	C017: Dementia Training for Carers in North Hampshire.
W004: Dementia friendly Plymouth.	E002: Admiral Nurses in West Sussex.	W021: Delivering a Stimulating Hospital Environment in Bristol.		C015: Dementia: from Difficult Conversations to Better Outcomes.	E023 Specialist Link Nurses in Surrey Downs.	C025: Medicine Optimisation in East Berkshire Care Homes.	
C056: Living well with dementia in the Isle of Wight.		C032: Making University Hospital Southampton Dementia Friendly.		E024: Improving End of Life Care for People Living with Dementia in Surrey Downs.			
E028: Dementia Friendly Communities in Guildford and Waverley.		C024: Reminiscence and Individualised Care Therapies in Windsor.					
W017: Dementia Friendly Communities in Somerset.		E038: Dementia awareness training in 12 community hospitals in Kent.					
C009: Dementia Friendly Communities in West Berkshire.							

Dementia Friendly Communities

3.4   The concept of the 'Dementia Friendly Community' has been promoted and developed by the Alzheimer's Society. Such a community,

"..is one that shows a high level of public awareness and understanding so that people with dementia and their carers are encouraged to seek help and are supported by their community. Such communities are more inclusive of people with dementia, and improve their ability to remain independent and have choice and control over their lives." [1]

3.5   As the PM's Challenge on Dementia pointed out, people with dementia want to remain independent for as long as possible, but 'the vast majority of people living with dementia' have a quite different experience:

"Not only do they frequently have to battle for diagnosis and support, but everyday things we all take for granted – getting to the shops, spending time with friends and family, getting money from the bank, and going on holiday – are made difficult because of the limited understanding of dementia in their communities." [2]

3.6   There is not just a single model for creating dementia friendly communities, as the varied experience of the DCF projects highlighted. From the outset, the DCF wanted to encourage sites to "adopt and adapt proven innovations and best practice". Typically, therefore, projects were building on established practice rather than starting from scratch. This was certainly the case with the Dementia Friendly Communities initiatives.

3.7   Some of the projects were notable for the scale of their ambition; thus W005, W004 and C056 were all attempting comprehensive transformation of their communities.   W005 (Integrated and inclusive communities across Cornwall) focused on approaches that would get the voluntary sector and businesses working together, and the impact was tangible:

"It feels sustainable, it feels as if it's community owned, and it feels as if we've got a huge array of organisations involved; and we've got some really key champions to move it forward. That feels really safe and hugely valuable, and a really good foundation for everything that we do." (W005)

3.8   The level of interest and engagement from sections of the community was a surprise:

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[1] http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1843

[2] Department of Health (2012), Op Cit, P.12.

"I'm also surprised at the level of activity in the community, at some of the alliances and evidence of intent to change. One printing company in a town saying that they'll provide printing free of charge for whatever is needed by the group; Specsavers saying they'll train all their staff; Eden project being really excited. [It has been] easy to win over hearts and minds, which I thought would need more of an effort to get going; the community enthusiasm has been more flourishing than expected." (W005)

3.9   Dementia Friendly Communities typically involve multiple stakeholders and different strands of initiatives, usually being brought together by a coordinator. A befriending project between communities and hospitals was also a feature of the initiative in Cornwall, intended to create opportunities for people with dementia to be befriended or to act as befrienders themselves. This part of the project had been slower to get established for various reasons, but important conclusions had emerged:

"There was also a misconception that people with dementia can't be befrienders for other people with dementia – we needed to support and challenge the provider about that. And we also needed to make sure that the message going out to people with dementia and their carers made it clear that they would be supported in being befrienders, and that that would be possible. So there have been delays, and I think we were quite ambitious in the number of people we expected to reach."

3.10   Sometimes apparently simple ideas – such as using befrienders to support people with dementia in hospital and following their discharge home – were complex in practice. Using befrienders in such capacity required compliance with hospital volunteer governance processes. It was also evident that general experience in befriending in the voluntary sector did not necessarily simply transfer into befriending for people with dementia, and required considerable investment of time and planning in order to develop.

3.11   The Dementia Friendly Plymouth project (W004) similarly built on a range of activity that was already taking place, involving many enthusiastic volunteers (including an awareness raising programme through the library service, an existing befriending scheme and a schools programme). The DCF application was submitted to enable Plymouth City Council (PCC) to take a role in bringing together all the various activities to develop Plymouth as a Dementia Friendly City and to link with the commissioning of dementia services. The key objectives were described in these terms by the Project Lead:

"Reducing stigma...hopefully eventually people with dementia will be able to get involved in all the activities that everybody else gets involved in, with no stigma. So it was really just about seed funding all of that...we aim to change the culture of the city."

And as the coordinator observed:

"Creating a Dementia Friendly City is good for everyone...we want a city that supports and engages all of its inhabitants."

3.12   Bringing about cultural change on such a scale is a major undertaking and a significant ambition. It was a recurrent theme across many projects, and is a topic we will return to below.

3.13   The project has been concerned to develop a coherent approach to dementia across a number of dimensions. The Dementia Friendly City Coordinator role has been a crucial element in drawing together different strands of activity under the umbrella of the Plymouth Dementia Action Alliance. The Chair of the PDAA described the significant aspirations of the project:

"Our dream was to make Plymouth the first Dementia City in the UK; along that road to achieve that dream, organisations, businesses, voluntary and private agencies, individuals with dementia and their carers have given their time and energy for free to put Plymouth on the map."

3.14   It is apparent that a key component of the activities and services has been the success of training in dementia awareness (led by the Alzheimer's Society). In the early days of the project the coordinator explored some of the circumstances that lead to people with dementia being marginalised and excluded. Local transport was identified as particularly important, with the result that the two local bus companies have produced 'Help Me' cards for people with dementia to carry to alert drivers to their need for a bit of time and understanding. In one company all the bus drivers have received Dementia Friends training, and this is now part of the induction for new drivers, the other company is also introducing Dementia Friends training. As the coordinator explained, awareness for drivers is key:

"Taking two seconds to allow someone to sit down before they move off can make the difference between that person coming out and doing that journey again or not."

3.15   A distinctive feature of much dementia friendly community work is the breadth and depth of engagement; this is particularly striking when it involves people and organisations for whom

dementia is not part of their core business. In Plymouth this was evident, for example, such stakeholders included dental hygienists, solicitors, and a local basketball team.

3.16 Evaluating the impact of such disparate initiatives is complex. The project coordinator explained that because parts of the programme existed prior to the DCF funding, separate evaluation was underway. Moreover, it is believed that the Dementia Friendly Plymouth programme is at a relatively early stage – there has been a lot of activity (dementia awareness training etc) and publicity, but it has yet to be judged what difference this has made for people living with dementia and their families. At the time of our fieldwork (February 2014) plans were being developed to gather baseline data and collate feedback. The coordinator post is being funded by the City Council for a further year to embed the approach further. However, the scope and scale of activity indicates that the model has been widely embraced by the community, and appears to be having a positive impact, as the project lead described:

"It's not complicated, it's not difficult; it's common sense. It's very straightforward to take action on this, and it has really big benefits....you can change small things which can have a really big impact."

3.17 The initiative across Plymouth was also distinctive for its engagement with schools. Nationally, the PM's Challenge on Dementia has recognised that schools and colleges have a particular role to play in creating a dementia friendly generation of the future. Since September 2012 twenty one 'pioneer group schools' have been developing ways of focusing on dementia within the curriculum; one such school is the Stoke Damerel Community College (SDCC) in Plymouth which has developed a wide range of projects across the curriculum including: art students producing posters for the City Library promoting Plymouth as a Dementia Friendly City; health and social care students going into care homes to make memory boards with residents; media students developing campaign videos about dementia; mathematics students designing games for maintaining and developing memory; English students training as storytelling facilitators with people with dementia; and students and care home residents playing intergenerational croquet during physical education classes at the school. Teachers we interviewed recounted the positive effects on students, including enhanced social skills, and students taking home information and understanding of dementia and disseminating it across their families and communities. As the Dementia Lead for SDCC commented:

"It's just magical, and that's the same magical thing that [the Head Teacher] was talking about in the croquet, when you step back and see a Year 7 [student] adapt the game to the

needs of the person playing, and that closeness and that bond, and that eye contact. The PE teacher leading it, the first time we ran it, was almost in tears, because it was such an amazing thing to witness."

3.18   The project 'Living well with dementia on the Isle of Wight' was another that had a global and wide ranging ambition, and recognised that much of this goes far beyond a traditional health remit, as the project lead described:

"I was really keen on the idea that if somebody was in distress at any place on the island, that people would have an understanding to be able to feel comfortable to approach and to know what to do....I was very keen to take quite a lateral approach, probably much wider that what most CCG commissioners would think of as pure health. So I was interested in galvanising all of the partners across the piste who had a part to play."

3.19   In this scenario, the project featured multiple dimensions including the development of a new dementia Care Pathway; dementia support workers; awareness training; memory groups; Alzheimer cafés; developing safe havens and Circles of Support, and engaging with schools in intergenerational work. As in Plymouth, there has been particular engagement on the part of the local bus company, and the development of 'Safe Journey' cards for people to show to drivers.

3.20   As with many other projects, although data collection was underway, it was still early days and hard evidence on effectiveness was not yet available. Nonetheless, qualitative data and feedback was providing a positive picture, indicated that the initiative was highly valued by people with dementia and their families, and indicated significant benefits of the project overall. A visit to a Memory Café during our fieldwork enabled observation of a relaxed and friendly atmosphere and good interaction between people living with dementia, their carers and café support workers. Carers made many positive comments to the researcher about the value of the café, for example:

"A real life-line."

"Stops you getting depressed."

"[the café] has changed our lives."

3.21   A key part of the success was attributed by the project lead officer to the successful partnership between different organisations; a lot of effort had been invested in the early days of the initiative to build relationships and trust, and this culminated in the application to the DCF ("I asked them to go away and be incredibly creative"). The size of the island

clearly offered benefits in terms of personnel knowing each other both within and between organisations, and easing some of the networking processes.

3.22 The level of commitment and passion was also apparent on the part of other key personnel, and this remark from a Dementia Support Worker was typical of many:

"It's a very people-orientated role, and I like to feel that I'm doing something that makes a difference...I must say, I love my job; love it, love it!"

3.23 The experience of development to-date was being used to make a case for recurrent funding locally to continue to take the initiative forward, to consolidate experience and ensure longer term sustainability.

3.24 Another model of 'Dementia Friendly Community' project was that underway in Guildford and Waverley (E028), which was part of a wider initiative covering the whole of Surrey, with three participating CCGs working in cooperation with the County Council. Public awareness has been a key feature of the work, for example with 80,000 households leafleted with 'Myths and Facts' about dementia. As with the other Dementia Friendly Community projects, there had been positive reception and engagement from other parts of the community and local businesses.

3.25 In Somerset there was also a county-wide dementia strategy group, and a background of work already underway. The challenge in moving forward was described by the project manager:

"We wanted to look at being dementia friendly, and Somerset is quite big, so it was well how are we going to do this and be able to make some kind of an impact locally."

3.26 An overarching project was developed with four work streams coming together (local network; dementia friendly community; training, and improving the hospital experience). A large part of the funding was put into recruiting people to posts and seconding others from the mental health trust, all of which took some time to achieve. However, having got people into post, it was recognised that this brought risks of continuity and sustainability as the 12 month period drew to a close. The challenge was around maintaining the model and way of working, and indeed rolling it out to other GP Federations across Somerset, as the manager described:

"Whilst I might have some concerns about the funding coming to an end for some of these posts, I'm hoping that the members of the Steering Group and people on things like the Dementia Strategy Group are going to be the people that can actually help other areas to

expand it or set up their own area. So we might lose potentially the people who were doing the work, but actually we're not going to lose the experience that we gained."

3.27   The initiative was feeding into the priorities for the county-wide dementia strategy over the next three years. Attention was also being directed towards evaluating impact but it was recognised that changing the nature of the community response to dementia was not something that was amenable to hard measures or indicators, but rather:

"It was more around that 'community feel' – the fact that more people are aware of dementia, and those are quite difficult to quantify."

3.28   Some additional – and unexpected – benefits were also identified, and in particular:

"A spin-off from this is about how we can make our organisations dementia friendly."

3.29   Raising awareness and creating greater understanding of dementia across the community is an important stage in developing Dementia Friendly Communities, but it *is* only the beginning. As the project manager commented:

"We've got the engagement going; we've got people understanding. For me, it's about how we actually change things now for people on the ground. And that's going to be when somebody <u>does</u> feel part of their community and they <u>do</u> feel supported, and I know that's going to take a long time."

3.30   This underlines the necessity – as we have already highlighted – of bringing about fundamental cultural change:

"It's about that people and their carers can live in an area that's dementia friendly, so it just means that other people understand them, they will help them access local services or facilities, and how they can best be supported to do that."

3.31   The Dementia Friendly Community project in West Berkshire (C009) was distinctive in focusing particularly on intergenerational work with primary schools. In common with the other Dementia Friendly Community projects we have examined, prior to the application to the Dementia Challenge Fund, there was a very active stakeholders group (involving the PCT, the Healthcare Trust and three local authorities). The bid involved all three authorities but we were unable to establish contact with two of these, and key people who had originally been involved in the project had since left post.

3.32   The project had identified the importance of engaging with children and young people when trying to influence change:

"Getting people, young people both to understand more about dementia and to become involved in projects (...) and having some contact with people with dementia (...) just to make sure they understood dementia and its impact, but also that they weren't frightened."

3.33   Working with children and young people fitted in with the project's central concern that dementia is – or is likely to be – part of everybody's future in some way:

"We need to be thinking now about what we want for people with dementia because at some point that could affect you, your family, whatever. That, I suppose part of the message is that dementia now is what cancer used to be in terms of perceptions and the need to kind of resource services and research."

3.34   A youth worker was recruited to work with schools and began by running dementia awareness assemblies (based on the 'Dementia Friends' model of the Alzheimer's Society) which explained what dementia is, and turning the understanding into action by looking at what people can do to make a difference. This then led to a range of bespoke intergenerational projects bringing together the schools and a local residential care home:

"My role was to help arrange things – we did a number of different activities; things like the students were doing cake decorating with people living with dementia in a care home; and in December we made some Christmas decorations in the care home and put them up around the home. So the people with dementia and the children did that together."

3.35   The coordinator's role was to provide the initial links between the school and the local home or day care centre, and then gradually to step back as things became more developed. In fact the coordinator had left post because of uncertainty over future funding but there were signs the work was ongoing with parents wanting to help things continue.

3.36   The experience with the project was highly positive, with the young people 'taking it all in their stride' and being very comfortable with interacting with people with dementia. The project apparently had significant impact:

"It got children chatting about it and in a relaxed environment and we talked about it and we broke down that stigma and I honestly believe that the young people that were involved in that scheme will have a completely different attitude (...) and a number of them said, you know I'd like to work in a care home (...). It really felt like a sort of a learning experience but a life experience for them at the same time."

Living well at home

3.37   The two projects with a primary focus on 'Living well at home' (W024 and E002) were both concerned with improving the response to the needs of people with dementia. W024 ('Enhanced, more responsive and preventative community based care in Gloucestershire') approached this by establishing a reablement team and a mentorship programme for senior reablement workers, and aimed to "increase the competence and confidence" of people in the team, providing them with appropriate resources to work with people with dementia, and signposting carers to local opportunities and education.

3.38   The Gloucestershire project learned from earlier experience and was careful to avoid establishing roles and services that would then end with the funding, and "we had to set up things that were going to be sustainable."   The project has had some positive impact but also encountered implementation difficulties associated with structural changes in the NHS and the mental health team, as the project lead commented:

"There were also big structural changes that affected the reablement teams, and then we come along and ask them to work slightly differently. They understand the relevance and importance for the service users with dementia, it's not a lack of willingness, it's just that there are so many competing demands that they're trying to process – we didn't always come out the winner."

3.39   The resources that had been developed to support the reablement workers appear to have been useful and valued. The project encountered some resistance to the idea of the materials at the outset with concerns about workbooks adding to workload, but in practice they have been valuable in helping people with issues such as recognition of delirium in people with dementia. The learning from the project is also being embedded across other local services and clinical pathways.

3.40   The Admiral Nurse project in West Sussex (E002) was also focused on supporting people in the community and providing "wrap around care". However, implementation had been significantly delayed because of difficulties in recruiting to the nurse positions. The project had been reconfigured to develop an 'Active Thinking Team' (not requiring a clinical background) to find new ways of supporting people with dementia and their carers; signpost to services; raise awareness of available support and reduce stigma. Despite the problems in getting the project off the ground because of inability to appoint Admiral Nurses, the process of developing a way forward had been very productive, involving excellent collaborative working through a Task and Finish Group.

Living Well in Care Homes & Reducing Anti-psychotic Prescribing

3.41   As we have noted previously, most projects addressed more than one of the main topics of the DCF, and here we have integrated analysis of the projects focused on living well in care homes and those concerned with reducing anti-psychotic prescribing, because there is a high degree of overlap.

3.42   The West Berkshire Care Home In-reach Team (C007) was developed to support care homes in caring for people with dementia and to avoid wherever possible unnecessary hospital admissions. This had a number of dimensions, including advanced care planning; quality of care within the home; level of activity and general environment; and the skills of care staff. The idea of in-reach could have been threatening and off-putting for care staff, and certainly in the early stages of the project there was some anxiety and defensiveness, but this soon dissipated as people saw the value of the approach.

3.43   The project discovered that frequently the decision to send someone to hospital is *not* (contrary to what had been believed) initiated by homes being risk-averse. Rather, the system seems to encourage admission, particularly when issues arise out of hours, and GPs tend not to want to visit but will advise homes that if a situation looks serious a person should be admitted to hospital. It was evident that attitudes and understanding needing to change in many areas, not only within the care home. This was believed to be happening:

Working with GPs and other services, e.g. district nurses. In a couple of care homes there's been a shift in attitudes, a cultural shift about caring for people with dementia (...) we've had feedback from other professionals who have gone into the homes and they've noticed that shift and change of attitudes."

3.44   The team leader for the project commented that care homes are used to being criticised, and a key part of the in-reach role was to tell care workers what they were doing well and to build their confidence. One direct result of this was believed to be a reduction in the use of anti-psychotic prescribing because staff had the skills to understand and respond to people's needs. From the perspective of care home managers, the involvement of the in-reach team was also seen as highly beneficial. The team's involvement had streamlined arrangements and made earlier intervention possible rather than 'having to go back and forth between health and social care' and wait for referrals from GPs, the team was able to provide responsive clinical help and advice. The project had also helped homes develop more consistent care and to offer a 'more complete service', which had been recognised by residents' family members who saw staff being more supportive and better attuned to needs.

3.45   The benefits to staff confidence were also acknowledged:

"So we have been able to upskill staff so that they can talk to the clinicians and point things out to them that they might not have been aware of. We've been able to empower staff to communicate more effectively with clinicians and they (the In-Reach Team) have been really good at supporting us to do that."

3.46   As another interviewee remarked, the impact on staff also began to bring about wider cultural change within care homes, for example:

"It's made staff look at what they do. You get some staff who are sceptical, who aren't that interested in changing what they do, but also the ones who are really keen to work as best they can. So the latter are really engaging with the team; and what is starting to happen is that positive influence from the staff who are really up for it is now starting to rub off on the other staff, and the other staff are getting really confident."

3.47   Demonstrating the achievements of the project was work in progress; qualitative data had been gathered from managers, care staff, residents and their relatives, GPs and social services. Facts and figures were proving harder to pin down:

"[We are] collecting the number of EOL care plans, activating 'All about Me' forms, reduction of anti-psychotics. But quality of life impact is really hard to capture. We know how many people we've assessed, how many we've reviewed, how many care plans we've changed."

3.48   The Medicine Optimisation project (C025) was specifically concerned with reducing the prescription of anti-psychotic drugs in East Berkshire care homes. The project was led by a Care Homes Prescribing Support Pharmacist who was explicit about the importance of the work in improving safety and wellbeing for residents with dementia. The use of anti-psychotics to control challenging or disruptive behaviour of people with dementia is widespread, but carries significant risks ("three times the risk of having a stroke; twice the risk of dying from it"). Prescribing guidance was developed for GPs and practice guidance for all care staff in responding to behavioural and psychological symptoms of dementia (BPSD), and training events for care home staff were organised. The objectives were twofold: to make people aware of the risks of anti-psychotic drug prescribing, but secondly to empower them with the skills to use alternative approaches.

3.49   As with some of the other projects we examined, it proved impossible to recruit someone specifically to undertake the project work, so in this instance the Prescribing Support

Pharmacists took it on in addition to normal work demands. The qualities and hidden skills of many care home staff emerged in the course of the work when people came to a second training event to reflect back on how they had used the training in practice.

3.50   Subjective evidence and feedback indicated that the training was having an impact in changing the approach to responding to the needs of people with dementia.

"[People have said to me] We have seen a change in terms of behaviour of staff towards residents and the way they care for them (...) they've seen a difference in how care plans are being written out."

3.51   Subsequent medication reviews provided further evidence of impact with low dose anti-psychotic prescribing down by about a third; at the time of the fieldwork further follow up of prescribing data was still awaited as there is considerable delay in being able to access ePACT (electronic prescribing) data. Benefits were also identified in improved networking and communications across health and care, and in the value of the training being recognised and rolled out in other locations:

"I don't know how many strokes we've prevented; I don't know how many premature deaths we've prevented, but what I definitely do know is that we have got local people all talking to each other now from various sectors."

3.52   The other project focused on improving community care and reducing anti-psychotic prescribing (E038) brought together a range of initiatives and projects targeted on improving quality of care in care homes and in community hospitals. As with C025, this group of projects trained a wide range of staff to equip them with skills to respond more appropriately to BPSD through person-centred care. The impact of change was being monitored through a range of performance measures including: number of aggressive incidents; falls; admissions to hospital etc. The detailed outcomes from this were not available at the time of the fieldwork.

3.53   It was apparent, however, that there was a variable response in care homes – "some have really embraced the project, and others have still to come on board." It was also evident that care workers needed confidence in their own skills to be developed, and when they undertook the training they were often self-deprecating ("I'm just a care worker"), and had "little understanding of how important their role is." It was also clear that change could be achieved relatively easily and as a trainer observed "staff don't need an awful lot of learning to really make a difference."

Better Care in Hospitals

3.54   The five projects primarily focused on improving hospital care for people with dementia were addressing – explicitly or otherwise – the aims of the national dementia CQUIN (Commissioning for Quality and Innovation) Framework. The national framework had defined the goals for dementia around identifying people with dementia; assessment and investigation, and referral.[3] In addition, the projects were also concerned with improving the general environment for patients with dementia and enhancing quality of care.

3.55   Reflecting some of the wider objectives, project W016 had adopted the title of 'CQUIN Plus' to describe its approach to integrating hospital and community pathways in Bath. Dementia coordinators were appointed (on internal secondments) to identify patients admitted with dementia and ensure they are on the correct pathway; liaise with carers, and provide appropriate personalised care (including completing the 'This is Me' document developed by the Alzheimer's Society). A training programme for hospital staff had also been introduced to increase general awareness of dementia: "Our aim is to be a dementia-friendly hospital, not just to have dementia-friendly wards." The 'Forget me not' flower symbol had been adopted to indicate on wristbands when a patient might have memory problems. If the person had to move wards for any reason staff would be instantly alerted to their needs and be aware that the person might be anxious or need information to be repeated or explained differently.

3.56   The coordinators also have access to support services and a fund to facilitate timely discharge, which might include arranging appropriate technology (such as door sensors) to support people remaining independent in their own homes. In practice it had proved difficult to use the discharge funds creatively and speedily because of the change it demanded in established practice:

"We've had to contract with a lot of different care agencies separately. It's been a whole lot of work; working with our accounts team and transferring the money (...) to get really beefed-up packages. And also to get our social workers to think about working with the Dementia Coordinators, rather than them thinking that what is being suggested is a bit risky – actually to think a bit laterally and work out what we can do together, using the discharge funds. So it's a big cultural change; but now we're using the funds, and we've got all the contracts set up."

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[3] NHS Commissioning Board (2013), *Commissioning for Quality and Innovation (CQUIN): 2013-14 Guidance.*

3.57   The team leader was in no doubt that the project had made "a massive, massive difference" and believed the model was one that "should be spread across all Trusts." Reduced length of stay figures, and fewer incidents on wards appeared to be providing concrete evidence of achievement.

"We know that people with dementia always used to stay between 5 and 10 days longer in hospital than their peers, and we know that we have managed to reduce that (...) We also aimed to reduce readmissions by 50%, but that was quite a hard task (...) we're not seeing a trend of patients being readmitted because of social breakdown, it seems to be more due to medical reasons."

3.58   Monitoring of qualitative indicators including carer involvement and staff attitudes were also providing positive feedback:

"The quality markers for carers feeling involved and getting the right information, and having the right communication with staff generally has really improved, so we're very pleased about that."

3.59   Rather than being a project that would run for 12 months and then finish, W016 believed they had accomplished a change in staff awareness and approach that was now embedded in the routine processes of the Trust. Local funding had been secured to continue to fund the Dementia Coordinator posts for a further year and build on the achievements to date.

3.60   One of the projects funded as part of E038 involved dementia awareness training across 12 community hospitals in Kent. Basic awareness training was aimed at all staff with patient contact (including domestic and ancillary staff), and focused on influencing attitudes, and values as well as providing basic knowledge. Hard quantitative data on outcomes was not available, but as the project lead commented:

"We know people living with dementia have significantly longer lengths of stay in comparison to other groups, and I believe that this can be due to the care provided as opposed to the person living with a particular illness."

3.61   It was expected that there would be benefits in reduced length of stay as a result of the training, and better understanding of the needs of a person with dementia. The impact on the incidence of falls was also under scrutiny, although it was recognised that this is far from straightforward, and indeed improvements to ward environments and awareness training can lead to an increase in falls, partly because of positive risk taking and increased

mobility. Although data was not yet available to demonstrate any trend with falls, the project lead believed they were leading the way:

"on falls innovations for all patients and any data generation will reflect this. An example is wrist bands for all patients at certain risk levels, significantly reducing fall rates."

3.62   W021 ('Delivering a stimulating hospital environment in Bristol') aimed to enhance the hospital environment by improving way finding and to reduce wandering of patients and their risk of falls. This was a small project (£15 K) and the money was used to provide adjustments such as colour coding, clearer signage, handrails etc. It was recognised by the project lead that "a little funding can go a long way" in making a difference. A parallel project in another hospital had run into problems in getting adjustments made that were not part of the original PFI specification for a new build hospital.

3.63   A similar approach to refurbishment and ward environment had been developed in Southampton (C032, Making University Hospital Southampton dementia friendly). The project was addressing not only the physical environment but was also including training for staff to improve person-centred care (including roll out of 'This is Me' booklets) and support for carers of patients with dementia (including establishing a carers café). Almost 800 staff received classroom training to improve their skills and knowledge of dementia, and information was cascaded to more than 5000 staff through specially produced information leaflets. Five wards (care for older people) had been targeted for intervention, and although this had been beneficial it was recognised there was a much larger task remaining to get buy-in from the rest of the hospital. Plans had been developed to extend training to all Trust staff over a three year period.

3.64   As we have highlighted with several other projects, C032 had significant start up problems associated with nursing staff recruitment. This led to a change in the specification for the pathway facilitator role and resulted in appointment but not until October 2013.

3.65   Internal evaluation of the outcomes of the project demonstrated improvements in carer satisfaction (with 72% reported as dissatisfied/very dissatisfied at the outset, and 61% satisfied or very satisfied at the end). Staff also reported greater confidence in responding to the needs of people with dementia; this was evidenced in the significantly reduced use of a 'specialling' budget to employ external staff to address challenging behaviour etc, because staff were now better able to respond appropriately to such needs. It had been anticipated that other outcomes would include reduced length of hospital stay; reduction in

falls; and more patients returning home rather than to permanent care. These outcomes had not been evidenced and the project team planned to review the success criteria.

3.66   The final project that we examined under the main heading of Better care in Hospital shared a number of features of the projects that we have already highlighted; however, C024 also brought a unique and distinctive dimension in focusing on the contribution of reminiscence and individualised care. The project lead was part of a small mental health team in an acute hospital, who had realised that dementia "was the biggest need in the hospital," as he explained:

"When I came into post I looked at all the facts and figures – people with dementia stay longer (...) but I can't find any evidence that says why."

Part of the explanation would seem to be in the loss of skills and increased institutionalisation that happens very rapidly:

"So if we can motivate people a bit more in hospital, it's going to improve their moods; it's going to keep them doing things and we'll get them out quicker. But even if it doesn't get them out quicker, their experience in hospital will be better."

3.67   Initially the project had planned to make use of a RemPod (a 'pop up' reminiscence pod)[4], but in practice it was problematic to introduce the pod on a ward environment ("Health and Safety. Infection etc"). A small room that wasn't being used was located in the hospital; appropriate wallpaper applied, and the contents of the RemPod (1950s TV, radio, living room furniture, decor and memorabilia) installed. Once established, the room was known as The Sunflower Lounge and patients with dementia can be brought from wards to spend time in the room with a staff member and volunteers to encourage interaction.

"For up to two hours, that's kind of long enough for people, and then it's back to the wards, and they just love it! And we can use it for people who are maybe a bit more confused, walking about and they really need an intervention. We can use it for people for are feeling quite down for whatever reason."

3.68   The model was also being rolled out into a bay within a medical ward where there was an attempt to create a more personalised and homely environment with softer colours for patients with dementia, and a television able to run 'My Life' software (a digital

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[4] http://www.rempods.co.uk/index.html

reminiscence system that includes music, interactive games and enables people to build their Lifestory).[5]

3.69   Qualitative measures of the success of the Sunflower model include collating comments from patients, but staff were also utilising the Likert Scale to assess patients' mood before and after using the lounge:

"The average scores before they go in are 4 and the average scores when they came out were 8. So that's 8 out of 10 – and there's your evidence that it works!"

3.70   Alongside the development of the Sunflower Lounge, the team had been involved in providing dementia training for hospital staff. This is both to explain dementia and its symptoms to people, but also to challenge staff on how they perceive and describe people with dementia:

"I think if we're going to change as an organisation, it's not just about having nice flooring so people don't slip; we've got to change everything."

3.71   Some of the benefits of training were evident in anecdotal evidence which underlined the way knowledge and understanding could empower front line staff, for example:

"I was on one of the wards and the matron said to me they had a patient in and he wasn't drinking, and a healthcare assistant there had been on the training day. Off her own back, she went off to a Pound Shop and bought a coloured beaker for him and he drank a litre of juice! Wow – so it is getting there!"

3.72   As with other projects we have examined, C024 was concerned above all with understanding and meeting the needs of people with dementia "in their world", and putting in place adjustments in the environment and – above all – in the understanding of staff, to enable needs to be better recognised and addressed.

Improving Diagnosis

3.73   Improving the diagnosis of dementia was a feature of several of the projects that we have discussed above, but it was the prime focus of two of the projects we explored. C026 was concerned with improving early diagnosis of dementia across East Berkshire, and piloted the 'Memory Clinic' approach across three GP practices; the approach was subsequently

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[5] http://mylifesoftware.com/

rolled out to all 20 GP practices. Some initial resistance was encountered from some GP Practice Managers and other primary care professionals who were concerned the project would be a tick box exercise and would generate additional demands. However, the experience of the pilot practices was persuasive in encouraging participation. Qualitative evidence from patients and family members indicated that many people were reluctant to raise concerns about memory issues with GPs who they perceived as being too busy; practice nurses have since been trained to raise the issue with patients in the course of other health checks.

3.74   The specialist link nurses project in Surrey Downs (E023) was concerned to improve the diagnosis of dementia because the rate was believed to be low across Surrey. Link nurse practitioners have been employed to do initial screening and referral for assessment and diagnosis. Unfortunately, in common with many other projects, initial progress was delayed by recruitment difficulties and plans to appoint four link practitioners resulted in two and a half posts actually being appointed.

3.75   It was recognised that assessing the impact of screening and referral would take time to become clear:

"Certainly now we're starting to see the diagnosis coming through because it takes some months to kind of go through the assessment at primary care, then the assessment at secondary care, and then to get the actual proper diagnosis. It doesn't just happen."

3.76   The response of patients to the screening was mixed, reflecting some of the public stigma which attaches to dementia. Feedback had been generally positive, but while some patients responded positively and particularly welcomed being able to go to the local GP practice with which they were familiar, rather than having to go to a memory clinic for screening, others were more ambivalent or negative. As the project manager described:

"We can't force people to come in for their assessment (...) all we can do is identify the patients and write to them, and then obviously we can deal with the phone calls if there's any big sort of concerns or apprehensions (...). The response rate to screening was excellent in some practices and quite low in others. This reflects the fact that some people are ready to come forward and be assessed and to deal with memory problems, while other patients who are at a more advanced state of memory loss sometimes cannot deal with the news. It does *reflect their personal circumstances and the support and care they are able to get at home. Sometimes patients need time to come to terms with coming forward for an assessment and the outcome of that, which may not be positive."*

3.77   Some GPs were also sceptical about the value of screening ("why does anybody actually want to know they have dementia?"), and it was important for the project to be able to point to the benefits of early diagnosis.

3.78   In addition to improving detection and diagnosis, the project was judged to have additional benefits in improving working relations between practices and the CCG, and between primary and secondary care. Such opportunities might not otherwise have arisen:

"We're bringing pharmacists in; we're bringing the psychiatrists in; we're looking at things like shared care protocols. You know – all sorts of stuff that we would probably never have done otherwise if we hadn't had such a project that straddled all the different bits of primary care and secondary care."

End of Life Care

3.79   Three of the projects we examined were concerned with addressing End of Life Care (EOL) for people with dementia. Two of these were particularly targeted at addressing the issues of the EOL care pathway in residential care homes. The Cornwall project (W011) had spent two years prior to applying for the DCF funding developing the model and demonstrating that it was the right approach which had quality outcomes for people with dementia and reduced the need for hospital admissions (the EOL project was part of a wider initiative under the banner of W011 which also included the development of Dementia Care Practitioners in the community providing continuity of care and support to people from pre-diagnosis through to end of life). A team of EOL Care Practitioners was specially developed to provide in-reach to care homes and train staff in the skills they needed. The objective was to ensure that the approach would become embedded and would not be reliant on the team's continued existence and would therefore be self-sustaining (training had been provided to 40 care homes). The project lead described the core objectives thus:

"So that means liaising with the GPs, training the care home staff, having evening sessions for carers and relatives about what EOL care will be available for their loved ones. Having those difficult conversation, and then having the legal Best Interest meetings and making them robust enough so that everyone is happy with the outcomes."

3.80   If the Best Interest decision is that the person should be supported to die in the care home, everyone involved is aware of the decision and inappropriate hospital admissions can be avoided. Particular challenges for the project arose with the high turnover of staff in care

homes which necessitates repeat training as new staff are appointed. EOL Care Practitioners described working hard to build awareness and understanding with GPs, out of hours staff, and the ambulance service so that people would recognise the paperwork that had been completed. In the past if a GP was called out of hours to a care home, there was a tendency to 'err on the side of caution and admit':

"Now that the documentation is in place, they know that the person's wishes are clear, there's been a Best Interest meeting, so they're able to leave them at home. And we have some successful stories where this has happened where otherwise they would have been admitted to casualty, and would have spent their last hours on a trolley or in the back of an ambulance."

3.81 The documentation doesn't only address matters such as resuscitation and medical intervention, but it also gives scope to record specific personal details such as people's musical preferences, and how much involvement a person's family might want in the final stages. The project has been able to achieve very positive results to support staff to recognise end stage dementia and to provide compassionate care that enables people to end their lives peacefully in the place they choose. Hospital admissions from care homes were believed to have reduced across Cornwall by 16% "and some of that is down to the project."

3.82 E024 was similarly concerned to improve end of life care in care homes, to reduce hospital admissions and improve advance care planning. In this example, the support to care homes was provided through a hospice introducing the Gold Standards Framework for Care Homes (GSFCH). This involved the hospice delivering training through a facilitator who also goes into the care homes to support implementation. Some of the care homes have taken the information and "flown with it" while others have "needed more encouragement and persuasion."

3.83 The impact of the project was being assessed by auditing deaths in the care homes and by examining qualitative data:

"We know that there have been really good improvements. One of the strengths of the GSFCH is that it does change organisational culture, and we've seen that. The care homes have a huge turnover of staff, and one of the proven results of the programme is that it reduces staff turnover, so that is a real selling point for us."

3.84 Because the programme was seen to bring positive outcomes it had been decided to build the facilitator post in workforce planning at the hospice and to fund it from the core budget.

The DCF funding had enabled the hospice to progress the GSF much faster that would otherwise have been possible:

"We would have got to it, but it would have involved forward planning into budgets etc which would have delayed it probably for a year or more. So, I'm really pleased that we've been able to get it up and running and prove its benefits very quickly."

3.85   The third EOL project was based around enabling GPs across 20 practices to recognise the importance of having 'difficult conversations' with people with dementia while they still have the capacity to do so. The project also highlighted the fact that dementia can't just be approached like any other disease "because of its impact on how you care for people with dementia who also have other conditions or problems." The project lead remarked that:

"I saw this as an opportunity to get into practice and connect with my colleagues, rather than only the enthusiasts. So we could say to the whole practice, we will meet you in your surgery and talk to you about these difficult things."

3.86   Around half of the practices had so far engaged with the opportunity to take part in a National Council for Palliative Care (NCPC) Workshop. Setting up arrangements for the workshops and getting GPs engaged took time ("there was some resistance"). It was challenging to make progress within the short space of time under the DCF. The lack of take-up by some practices was a surprise, even with the offer of locum support, although it was acknowledged that at the time "there was a lot of change going on and people were exhausted, and they just didn't want to engage at that time." It was believed that attitudes had shifted since, particularly as the benefits of the approach began to become apparent.

3.87   The project had also evolved beyond end of life planning and had also begun to address the care of people with dementia in care homes and to raise GP awareness of assessing stages in dementia and identifying progression. The project was viewed by the leader as very worthwhile, with particularly positive experiences of working with NCPC, and it was hoped that the work could continue.

Better Support for Carers

3.88   Support for carers has been an integral feature of much of our analysis above, and the great majority of projects recognised that supporting carers was a vital part of supporting people with dementia. Qualitative data across the projects was often cited to highlight the

comments that carers had made about the value of support and being recognised, for example:

"Some relatives get so much relief just to be able to talk about their loved one's death and what they want." (W011),

"I felt included and involved." (C026)

"I always knew who to talk to." (C032)

"We're putting into practice some of the tips we were given at the memory café, and they're working." (C032)

3.89   Only one project was aimed specifically and exclusively at supporting carers; C017 was intended to provide Dementia Training for Carers in North Hampshire. It was also the smallest project in terms of funding (£8 K), although it was part of a suite of 7 projects funded through the DCF across North Hampshire with a total budget of £293 K. Progress had been very slow. Training courses for family carers on 'Understanding Dementia' were to be delivered via the Princess Royal Trust for Carers and delays were apparently due to difficulties in recruiting trainers. The project was believed by those involved to have been "successful in the promotion and engagement with carers", and plans were in place to run the courses during 2014 (one had taken place at the time of the fieldwork).

4. Overview and Conclusions

4.1   We have explored the major experiences of the sample of projects using the eight themes of the DCF programme. We have presented the key findings throughout our analysis and we do not repeat these needlessly.   However, we would highlight the cross-cutting conclusions and messages that were identified repeatedly and which seem to carry particular weight. These include:

- Cultural change.

- Start-up and sustainability challenges.

- Organisational reform and disruption.

- Strong and inspirational leadership.

- Public engagement.

- Empowerment through skills and knowledge.

4.2   The NHS South of England Dementia Challenge set out to stimulate and encourage CCGs working with local authorities, the voluntary and independent sectors and other local partners, together with people with lived experience "to identify and implement practical solutions to the problems faced by people living with dementia." The cultural change that is required to establish genuinely inclusive dementia friendly communities is profound. This has implications not only for the health and social care economy, but for a breadth and depth of vision that embraces all aspects of society. This can include, for example, the built environment; public transport; high street shops and services; and schools and colleges. The experience of the projects has underlined both the challenges that this entails, but also the potential for transformation when the agenda is embraced across agencies and organisations. Successful innovation typically requires partnership between many different agencies, as this project lead observed:

"We can't do it on our own. This is a cross-partnership commitment, and we need to move from the bio-medical model, which doesn't work in this arena, to a psychosocial model (...) It's all down to the passion and commitment of a whole series of people – all I've done is to galvanise them and pull them together." (C056)

4.3   A key part of the cultural change is often around how an organisation views dementia, and moving this from being a separate specialism to a dimension which crosses all aspects of care and support, since people with dementia are likely to use different primary and

secondary care services. Projects that were concerned with living well in care homes, with reduced prescribing, and with End of Life care also illustrated the cultural change that was particularly associated with empowering care staff through better understanding of dementia, and equipping them to continue to support people in place rather than to refer them to inappropriate or unnecessary hospital care. Such empowerment reflected the wider cultural shift within organisations and how they view and understand dementia. Increased job satisfaction was identified frequently, with the added potential benefit of reduced staff turnover, particularly in the care home sector.

4.4   The achievements of projects have often far surpassed expectations. The intergenerational project (C009) found children and young people having completely different attitudes to dementia as a result of a short intervention and engagement with care home residents. In other projects too, interviewees commented frequently on their surprise at the level of interest and engagement of other organisations and agencies across the community. Active engagement with people who live with dementia and with their families and carers, and with the wider community have been distinguishing features of successful projects, particularly in tackling stigma and misunderstandings of dementia. On the national stage, the Prime Minister's Challenge on Dementia had set the target of achieving 20 cities, towns and villages signed up to be Dementia Friendly Communities by 2015. In fact, the second year progress report on the Dementia Challenge highlighted the achievement that 50 communities had so far signed up to become dementia friendly, and the target for 2015 had been revised to 75.[1]

4.5   Embedding cultural change will be vital if the achievements that have been attained are to be sustained and built upon. Many project leads and coordinators commented on their concern to avoid establishing practices and models that would be reliant on appointments that would end with the DCF funding. In many instances, as we have reported, projects were being brought within core budgets and being developed further by organisations that recognised their value.

4.6   However, start-up difficulties were reported by many of the projects, and typically these were associated with frustrated efforts to recruit and appoint project staff. Sometimes this had been avoided by people incorporating the project within their work remit, or by organising internal secondments. With projects that were funded for only 12 months, any delays in getting underway impacted significantly on achievements within that time frame.

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[1] http://dementiachallenge.dh.gov.uk/2014/05/07/champion-groups-letter/

Many projects argued that it would have made more sense to have a longer lead time, and it was too soon to judge achievements in many cases, and evaluation data was incomplete or still in development. Nonetheless, it was also evident that even within a short time scale projects *had* succeeded in delivering tangible outcomes and in opening local debates that were likely to continue.

4.7   The DCF was launched at a time of considerable change and turbulence in the structure of the NHS at local and regional levels. The removal of SHAs and PCTs from April 2013 caused the disappearance of structures, organisations and established networks. These observations were typical of many similar comments:

"With all the restructuring at different levels of the commissioning process, [it was] challenging to identify appropriate focus for the team's work. We worked to understand what the landscape looked like post-restructuring, it is still not stable, but different agencies are now starting to understand what their role is."

And

"The NHS keeps changing, and routes of accountability and (...) the organisation keeps changing its nature (...) you have new faces coming in and people who used to be doing something have moved off to do something else."

4.8   People who had been involved in putting together the original bids for DCF projects had sometimes moved to other posts and responsibilities by the time funding was awarded and projects needed to commence. For the review team this brought its own significant challenges in tracking and tracing projects, and for the projects themselves there was an inevitable hiatus.

4.9   A quarterly reporting process introduced by NHS South of England for projects that were successful in being funded through the DCF brought its own challenges. After April 2013 there was general confusion about the requirement to continue reporting, and where to submit the reports.

4.10   Despite the difficulties with reporting, it would be mistaken to assume that there were not governance processes in place. Indeed, most projects pointed to local reporting and accountability through CCGs, Dementia Partnership Boards and steering groups, and it was evident that the majority of projects were being routinely scrutinised and challenged, and were being brought within the wider vision of local dementia strategies..

4.11   Gathering evidence on achievement and outcomes was ongoing for most projects. This reflected the slow start that many had experienced in getting projects off the ground. It was also the case that projects needed to adjust their success criteria as they evolved, particularly when other achievements were identified. Because so many of the projects are concerned with developing approaches that require cultural change and new ways of thinking and operating, their achievements are not readily measured by KPIs or similar. Such projects were gathering qualitative evidence and were able to point to significant shifts in ways of working and approaches to dementia. Clearly, other projects do lend themselves more readily to quantitative assessment and measurement (for example, reducing the prescribing of anti-psychotic medication to patients with dementia).

4.12   Most projects were developing plans and making a business case for their continued existence, and as we have reported, in some instances CCGs had committed to taking the work forward. Securing ongoing support for work (beyond another 12 months for example) will continue to be challenging in a climate of economic restraint. However, in many instances projects had developed a momentum and had expanded the partners they were working with; had equipped a wide range of people with skills and knowledge, all of which created a likelihood of sustainability that was not reliant on the continued presence of a project manager or coordinator – other people had taken ownership.

4.13   Taken as a whole, the DCF projects have created myriad opportunities and achieved outcomes which – in many instances – are above expectation. It is important that the findings and learning from the programme are widely shared and disseminated. On an individual level, many projects were taking opportunities to highlight their achievements, and some local exchange of information and experience was facilitated at events (for example, by Windsor, Ascot and Maidenhead CCG, and by the Thames Valley Health Knowledge Team). However, many project leaders also commented on their wish to know more about the experience of others working in similar (and different) initiatives.

4.14   As with much innovation, the success and momentum of many of the DCF projects owed a great deal to the passion, drive, vision and persistence of project leaders. Such enthusiasm was infectious and inspirational, and was tangible. The final word goes to an EOL care practitioner who summed up the value of the work:

"We love what we do and (...) we will finish knowing that we have made a difference. Most people – it doesn't matter what you do, like to feel that you've made a positive difference, and we know that we have."

Appendix 1

NHS South of England Review of Dementia Challenge Fund: Reference Group

A Reference Group was established to advise on the approach and findings of the review. This was a virtual group that was consulted via email. We are very grateful to the members for their interest and engagement and for their helpful insights.

Dr Martin Ansell	2Gether Foundation NHS Trust	Consultant Old Age Psychiatrist
Dr Peter Bagshaw	South Gloucestershire CCG	GP and Clinical Lead for Mental Health, Dementia, Learning Disabilities and Safeguarding
Helen Bown	NHS Gloucestershire	Joint Commissioning Manager, Older People and Physical Disability.
Dr Peter Brindle	University of Bristol and Avon Primary Care Research Collaborative	GP and Senior Lecturer, Director Research and Development Programme.
Dr Nick Cartmell	South Devon & Torbay CCG	Associate Clinical Director (Dementia) South West
Derek Dominey	Alzheimer's Society	Carers Representative
Dr Chris Dyer	Royal United Hospital, Bath	Consultant Geriatrician & Clinical Lead
Dr Iain Lang	National Institute for Health Research	Senior Lecturer in Public Health
Anne Rollings	Alzheimer's Society	Involvement Lead, Alzheimer's Society South West

Appendix 2

Fieldwork: site selection and methodology

The 69 funded Dementia Challenge Fund projects were located across three regions in the south of England, namely, South East England (SEE), South Central England (SCE) and South West England (SWE). SCE had the largest number of projects (33), followed by SWE (20) and then SEE (16). The number of sites selected for further exploration in each region was proportionate to the total number in each. There were accordingly nine SCE sites, seven SWE and five SEE, making a total of 21 sites. This number was determined by considering a range of criteria, together with the feasibility of data collection involving three researchers within a limited time-frame. Questionnaire responses were available for all the sites chosen.

The first priority was to ensure that the sites selected would cover the range of allocated funding, as well as representing all eight themes. There were comparatively large numbers of sites addressing some themes, for example, community-based care, while for other themes, such as improving diagnosis, there were relatively few sites from which to choose. In these cases, all projects addressing those themes were selected.

Factors considered to be crucial to providing good care for people with dementia include the interface between hospital and home. For this reason, a few projects with that specific focus were selected. Projects appearing to have a unique focus, for example, technology libraries, were also initially included. Further selection was based on geographical spread within each region. A decision was also made to include one site from each region where projects had *not* been able to start on time, in order to explore factors affecting implementation.

Of the 21 chosen sites, four were selected for visits, as the researchers wished to investigate particular conditions operating within them:

1. A dedicated environment for people with dementia has been created within a hospital in Windsor, Ascot & Maidenhead (C024).
2. Changes have been made to the acute care environment in a Southampton hospital (C032).
3. There has been a drive to create a Dementia Friendly Community on the Isle of Wight, which involves initiatives based in the community as well as in acute settings within the island environment (C056).
4. A project is underway in Plymouth to establish it as a Dementia Friendly City, with services situated in public libraries and comprehensive engagement with schools (W004).

The visits involved interviews and discussions with 47 individuals in total. Time and financial constraints precluded more visits being undertaken. Interviews were recorded and observations and reflections on projects were captured by means of fieldnotes during or immediately after visits.

It was intended to conduct telephone interviews with project leads and, in some cases, other individuals from the remaining 17 sites. In practice this involved interviews being undertaken with 31 people. As there had been numerous changes of personnel since the project's inception, it proved impossible within the available time-frame to contact the project lead for 'Technology libraries in Bath and North East Somerset' (W014), which was initially included in the sites selected. During data collection, it became apparent that one of the SWE sites selected, 'An innovative model of care across the community and care home in Cornwall' (W011) was essentially a component of the project 'Integrated and inclusive communities across Cornwall' (W005). The latter project was therefore included in the selected sites. Table A.1 provides details of the 21 sites in which further investigations and fieldwork were conducted.

Table A.1: DCF Project sites selected for further fieldwork and data collection

No	SEE Projects	Funding (£K)	DFC	LWH	BCH	ID	EOLC	RAPP	BSC	LWCH	Rationale for selection
E002	Sussex Admiral Nurses	86									Not yet started.
E023	Specialist Link Nurses in Surrey Downs	249	✓	✓		✓					Focus on communication between professionals.
E024	Improving End of Life care for people living with dementia in Surrey Downs	58					✓			✓	Focus on EoLC and care homes.
E028	Dementia friendly communities in Guildford and Waverley	146	✓			✓					Community based. Public involvement.
E038	Reducing anti-psychotic prescribing in West Sussex	405		✓	✓			✓	✓	✓	Large amount awarded.
No	SCE Projects	Funding (£K)	DFC	LWH	BCH	ID	EOLC	RAPP	BSC	LWCH	Rationale for selection
C007	West Berkshire care home in-reach team	341					✓	✓		✓	Focus on care homes.
C009	Dementia friendly communities	33/190	✓	✓					✓	✓	Intergenerational.
C015	Dementia: From Difficult Conversations to Better Outcomes	111				✓	✓	✓		✓	Focus on GPs.
C017	Dementia training for carers in North Hampshire	8									Not yet started.
C024	Reminiscence and individualised care therapies in Windsor	17			✓			✓			Small amount. Dedicated environment.
C025	Medicine optimisation in East Berkshire care homes	80						✓		✓	Focus on medication.

Appendix 2: Fieldwork site selection and Methodology

No	SCE Projects	Funding (£K)	DFC	LWH	BCH	ID	EOLC	RAPP	BSC	LWCH	Rationale for selection
C026	Enhancing the early diagnosis of dementia across East Berkshire	21				✓					Small amount.
C032	Making University Hospital Southampton dementia friendly	280			✓				✓		Changes to acute environment.
C056	Living well with Dementia	260	✓		✓	✓			✓		Based in the community and in other settings. Island.
No	SWE Projects	Funding (£K)	DFC	LWH	BCH	ID	EOLC	RAPP	BSC	LWCH	Rationale for selection
W004	Dementia friendly Plymouth	110	✓	✓					✓		Specific community focus. Intergenerational.
W005	Integrated and inclusive communities across Cornwall	106	✓								Inclusion emerged from data collection for W011.
W011	An innovative model of care across the community and care home in Cornwall	446		✓		✓	✓		✓	✓	Large amount. Crosses acute/primary boundary.
W016	Integrating hospital and community care pathways in Bath	296			✓						Crosses acute/primary boundary.
W017	Dementia friendly community in Somerset	415	✓	✓	✓						Large amount.
W021	Delivering a stimulating hospital environment in Bristol	30									Not yet started.
W024	Enhanced, more responsive and preventative community based care in Gloucestershire	320		✓	✓				✓		Focus on carers as well as professionals.

DFC = Dementia friendly communities   LWH = Living well at home   BCH = Better care in hospitals   ID = Improving diagnosis

EOLC = End of life care   RAPP = Reducing anti-psychotic prescribing   BSC = Better support for carers   LWCH = Living well in care homes

Appendix 2: Fieldwork site selection and Methodology