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Slaying the Demon

The Dementia Challenge: Progress and Achievements

Executive Summary

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Executive Summary

Slaying the Demon¹: 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, and a full report is available². 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.

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).

² Henwood M, Butler T and Pollard K (2014), *Slaying the Demon: The Dementia Challenge: Progress and Achievements*.

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 75.³ 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.

³ <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.