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CENTRE FOR INTERNATIONAL
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New Approaches to Supporting Carers' Health and Well-being: Evidence from the National Carers' Strategy Demonstrator Sites programme

Edited by Sue Yeandle and Andrea Wigfield

CIRCLE

Centre for International Research on Care,
Labour and Equalities

University of Leeds

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Glossary of Terms

Alternative care	Care provided for the person a carer normally looks after while they attend their own appointments, training, etc. The care offered may be a few hours of home care or a session in a day centre or other non-residential facility.
Carer's Assessment	Most carers have a legal right to an assessment of their own needs. Carer's Assessments are the responsibility of social services, and explore the impact of the caring role, and a carer's entitlements to services and support.
Demonstrator Sites (DS) programme	Programme of support for carers developed and funded by the Department of Health (DH) as part of the commitments made in the July 2008 National Carers Strategy for Carers. The programme comprised 25 sites across England, focusing on three areas of support for carers: breaks; health checks; and better NHS support.
Direct payments	Direct payments are monetary payments made by councils directly to individuals who have been assessed as having needs that are eligible for certain services (including to people who care for others). Direct payments promote independence, choice and inclusion, by enabling people to purchase the assistance or services that the council would otherwise provide.*
Expert Adviser	People with expertise in support and services for carers appointed by the DH to support the work of the DS, provide advice on service development and delivery, and act as a point of contact between the DH and the DS.
GHQ-12	A version of the General Health Questionnaire which involves respondents rating themselves against a series of 12 statements, and screens for non psychotic-psychiatric disorders (such as poor mental health).
Local evaluation	Each DS conducted research locally to evaluate services. The scope and methodologies used varied, often including both qualitative and quantitative approaches. Most DS published their local evaluation report, and / or made it available to the national evaluation team.
Personalisation	A strategic shift in social care towards early intervention and prevention, empowering individuals to exercise choice and control over the services and support they receive, and providing services tailored to the individual needs of service users and their carers. The approach was set out in detail in 'Putting People First', a DH strategic document published in 2007.

Personal budgets	A personal budget is the amount of money that a council decides is necessary to spend in order to meet an individual's needs and direct payments are one way in which the person can choose to use that money in order to meet those needs. As well as being made as a direct cash payment to the service user, a personal budget may also be held in trust by a council or third party, who will arrange services as directed by the person requiring support (an arrangement often described as a 'notional budget').*
QoF points	The Quality and Outcomes framework (QOF) is a voluntary annual reward and incentive programme for all GP surgeries in England, detailing practice achievement results by giving an indication of the overall achievement of a surgery through a points system.
Respite care	Respite care is the term widely used in social care to refer to short term, temporary care provided (on a planned or emergency basis) in another setting (e.g. a hospital, nursing or residential home or specialist residential facility) for a sick or disabled person so that the (unpaid) person who normally cares for them can have a rest or break from their caring role.
Read coding	System used within the NHS to record, on a patient / service user record, certain characteristics including if the person is a carer.
WHO-5	The WHO-5 measures psychological well-being using five items covering positive mood (good spirits, relaxation), vitality (being active and waking up fresh and rested), and general interests (being interested in things).

* DH (2009) Guidance on direct payments: for community care, services for carers and children's services. London: Department of Health.

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Executive Summary

The National Carers' Strategy Demonstrator Sites (DS) programme was developed by the Department of Health (DH) as part of the commitments made in the 2008 National Carers' Strategy (HMG, 2008). The DS programme, delivered across England, comprised 25 partnerships. With a delivery period of 18 months, each site was expected to develop new, innovative services for carers, or to extend existing provision if effective arrangements were already in place. The programme focused on three areas of support:

- Twelve Breaks sites aimed to measure the quality and effectiveness of a range of new approaches to offering breaks to carers.

- Six Health Checks sites aimed to deliver annual physical health and / or health and well-being checks for carers.

- Seven NHS Support sites aimed to explore ways of providing better support for carers in a variety of different NHS settings.

The aim of the programme was for sites to develop and enhance the local support available to carers and, where possible, to measure the quality and effectiveness of the new provision. The national evaluation of the DS programme was commissioned to assess the extent to which these goals were achieved, with a particular focus on: mapping the Demonstrator Sites' activities; assessing the effectiveness of their initiatives; examining the impact on carer health and well-being; outlining the cost of initiatives; and assessing the extent of carer engagement in the planning, delivery and evaluation of the programme.

Innovation and effective practice

The 25 sites delivered a large volume of services and support for carers in new settings, via new or extended partnerships. Most sites developed new delivery approaches or other new ways of working, initiating at least some which were truly innovative. Many sites made significant changes to existing provision and local staff considered these made a positive difference to carers.

- The Breaks provision included: specialised short-term respite for carers of people with dementia / mental ill-health; imaginative use of alternative care in the home; and an extremely flexible approach to the delivery of personalised breaks.

- The Health Checks were offered as physical health examinations and well-being checks, delivered either in combination or separately. Some sites experimented with delivering checks using non-clinical staff and / or staff based in voluntary organisations.

- The NHS Support services offered new ways of supporting carers in hospital and primary care settings. They included befriending and peer support activities, awareness training for staff, and improving information, documentation, referral arrangements and access to Carer's Assessments.

All sites focused on making support accessible to carers. Breaks sites explored new approaches including on-line booking systems. Health Checks sites offered checks in a variety of venues including carers' own homes and local community centres. The NHS Support sites offered new ways of delivering Carer's Assessments and helped carers access a wide variety of other support, with particular emphasis on identifying carers not already in receipt of support, working in GP practices and in hospital wards and clinics.

Partnerships and multi-agency approaches

The vision for the future support for carers set out in the 2008 National Carers' Strategy involved significant change in the health and social care system, and the national evaluation provided an opportunity to explore the wider implications of this for the people and organisations involved. The sites found that developing new services had an impact on staff roles, multi-agency partnerships and working relationships. Impacts on staff were wide-ranging and included: improved teamwork; greater carer awareness; new activities (to engage with carers not previously in touch with support services); and developing new skills. Some staff reported an increase in their workloads, particularly those based in voluntary sector organisations and / or involved in outreach activities.

Staff experiences varied according to the different approaches to carer support taken in each site. Some staff delivered services in carers' homes; others had to work inventively to overcome colleagues' reluctance to engage with new services; some needed training to adjust to their new roles and working arrangements. Nevertheless, health and social care professionals reported few problems in integrating DS activities into existing roles and systems.

All sites developed partnerships which included voluntary sector groups, NHS organisations, and local authorities. Most Breaks sites were local authority led; the NHS Support sites were led by NHS organisations; and leadership arrangements in the Health Checks sites varied. Most partnerships were established formally, with organisations adopting specific roles and responsibilities. Some sites also developed flexible and comparatively informal networks to support outreach to carer groups not previously in touch with support or services.

Benefits of the DS partnerships included: improved carer support procedures; better monitoring systems; more effective communication networks across the health and social care system; and new carer awareness training for staff.

Difficulties were experienced in some partnerships. These included problems in reconciling different procedures and / or access to resources in partner organisations; a low level of commitment among some partners; concerns in some local voluntary organisations that carers registered with them might be drawn away, possibly undermining future capacity to attract funding; and differential engagement among GPs.

Changes in staff roles and in the work of the multi-agency partnerships had a generally positive effect on system responsiveness and on care co-ordination in the health and social care system, however, with a positive impact on the quality and accessibility of carers' services.

Identifying, engaging and involving carers

The 25 Demonstrator sites supported a total of 18,653 carers (5,655 in Carers' Breaks sites; 5,441 in Health Checks sites; and 7,557 in NHS Support sites). An additional 28,899 carers were contacted by the sites but did not receive services. Sites planned to engage with quite varied numbers of carers, and also varied in the extent to which their targets were achieved.

The profile of carers supported by the sites was of predominantly older, female carers. Sites were also rather successful in engaging carers in ethnic minority communities and carers of people with dementia, mental ill-health, long-term/terminal illness, learning disabilities and substance misuse problems.

Success in engaging carers was in part determined by the types of engagement initiatives selected. Although initially sites faced challenges in engaging GPs and other healthcare professionals, the partnerships involving NHS staff were often successful in identifying and engaging carers, particularly in the NHS Support sites and in some Health Checks sites.

Sites which succeeded in identifying and engaging large numbers of carers, and in meeting targets, used a combination of techniques, such as adopting tailored initiatives for target groups of carers. There was a widespread view among staff that avoidance of the term 'carer' in marketing materials was important when engaging with those new to support services.

Partnerships and networks played an important role in the sites' capacity to engage with carers. Innovative approaches designed to reach young carers through partnerships with schools, colleges, youth centres and universities worked well, as did outreach work through voluntary sector organisations to engage with ethnic minority carers. Gaining the trust of carers through face-to-face methods was often described as a more effective way of engaging with carers than using other strategies, such as using websites, advertisements, posters and leaflets.

All sites involved carers in service design and some also involved carers in project delivery and service evaluation. These carers offered alternative perspectives to those of social and healthcare professionals, raising some issues not previously considered. Some sites planned to continue developing carer involvement, with staff describing this as a significant 'legacy' of the DS programme.

Impact on carers

Information was collected on 5,050 (27%) of the 18,653 carers receiving DS services. This showed that these carers were more likely than carers in general to be older, female, to have been caring for ten years or longer and to be caring for 50 or more hours per week. Carers in ethnic minority groups were well represented, as were carers of people with particular conditions such as: dementia; mental ill-health; long-term / terminal illness; a learning disability; or substance misuse problems.

Some carers were surveyed to gain an understanding of how they experienced the DS services in terms of: how they became aware of the programme; whether they had received similar services before; what they thought of services; and how they felt their health, caring situation, and selected activities had been affected by engagement. Carers were positive about the services, and a majority said they would recommend them to other carers.

In the Breaks sites, 80% of carers responding to the survey had not previously taken a break of more than a few hours from their caring role. In the NHS Support sites, many carers had never before received support to assist them in their caring role. Most survey respondents accessing the Health Checks sites had seen a healthcare professional in the past six months, but the new emphasis on well-being and the more holistic approach taken in the DS programme was widely welcomed.

Accessing the Breaks services enabled some carers to have more of a 'life of their own' and to build confidence; some also reported changes in their behaviour which were beneficial for well-being or health. A third had started a new leisure activity, and some reported improvements in their communications with professionals and better knowledge of carers' entitlements. Carers who did not receive a break were more likely to show deterioration in well-being scores.

The health checks offered had a positive impact on a large minority of those supported. A quarter said that how they looked after their health and the amount of exercise they took had improved. Most had been signposted to additional services, though the responses of a few suggested care needed to be taken to ensure that other support for carers was appropriate.

Costs and benefits

Through the DS programme, the DH was seeking to gain a better understanding of which models of delivery and which kinds of carer support are cost effective in terms of direct provision and the wider potential cost savings in the health and social care system.

Total site costs and cost per carer supported varied both within and between the three different types of site. Although precise measurement of cost savings was not possible, the study found evidence that many of the types of carer support introduced had the potential to result in cost savings within the health and social care sector. Potential savings were identified in the national evaluation study and in the local evaluation reports, relating to:

- Preventing hospital or residential care admissions.

- Supporting carers to sustain their caring role.

- Earlier identification of physical and/or mental health issues.

- Improved health and well-being of carers.

- Improved partnership working.

- Efficiency savings in GP practices.

- Assisting carers to return to, or remain in, paid work.

- The establishment of informal support networks among carers.

Four sites calculated the cost savings of their services, using different approaches; each calculated positive cost savings. Many sites continued to offer all or part of the support services provided through the DS programme after their DS funding had ended.

Policy recommendations

1. In all localities, efforts to bring local authorities, NHS organisations and voluntary sector organisations together to develop and deliver effective support for carers, in partnership, should be strengthened.

2. Local carer support partnerships should involve a diverse range of carers in service development.

3. In delivering support to a wide range of carers and reaching carers not already in touch with services, local partnerships should work flexibly, and sometimes on an ad hoc basis, to engage carers in specific target groups.

4. Effective carer support at the local level should always include a varied portfolio of carer support services, which can be adapted to meet individual needs.

5. Portfolios of carer support need to be agreed locally between local authorities, NHS organisations, voluntary sector organisations and other organisations where appropriate.

6. Hospitals should routinely provide mechanisms to identify and support new carers, centring their efforts on wards where patients have received a new diagnosis or are due to be discharged and on out-patient clinics where patients are likely to be accompanied by those who care for them.

7. Every GP practice should be encouraged to identify a lead worker for carer support, who can assist in carer identification, help in referring carers to suitable local services, and ensure carers' access to health appointments and treatments is not impeded by their caring circumstances.

8. All staff who interact with carers, in hospitals, GP practices, local authorities and in the voluntary sector should be trained to consider how caring responsibilities can impact on a carer's health and well-being and equipped to advise on how a carer can access a health and / or well-being check.

9. All relevant organisations should regularly offer carer awareness training to their staff.

Chapter 1
The National Carers' Strategy Demonstrator Sites Programme

Sue Yeandle with Christina Buse and Viktoria Joynes

1.1   Introduction

The National Carers' Strategy Demonstrator Sites (DS) programme was developed by the Department of Health (DH) as part of the commitments made in the July 2008 National Carers' Strategy *Carers at the Heart of 21st Century Families and Communities* (HMG, 2008). These commitments included new measures to improve carers' health and well-being and were incorporated into DH financial plans in 2008-9 (DH, 2009:4).

The DS programme, delivered across England, comprised 25 partnerships, each led by either a local authority or a primary care trust (PCT) working in partnership with other local agencies. With a delivery period of 18 months, each DS was expected to develop new and innovative services for carers, or to extend existing provision if effective arrangements were already in place. The programme focused on three areas of support for carers: breaks; health checks; and better NHS support. The aim of the programme was for sites to develop and enhance their services and support for carers and, where possible, to measure the quality and effectiveness (including cost effectiveness) of the new provision. Particular emphasis was placed on demonstrating opportunities for the NHS to offer better support to carers. The DS gave support to 18,653 carers during the lifetime of the programme.

This report explores the extent to which the DS were able to meet their objectives and draws out learning from their experiences of delivering services to carers in new ways. It concludes with a set of evidence-based policy recommendations. This opening chapter includes a discussion of the shifting policy context in which the programme was commissioned, outlines the DS programme and objectives and highlights some of the wider changes affecting health and social care arrangements during the programme delivery period. It also provides details of the study methodology and of how the report is structured.

1.2   Policy context

In 1999, the publication of *Caring for Carers*, the first national strategy for carers, signalled central government's recognition that carers needed greater support than had previously been available to them (HMG, 1999). A range of new policy developments followed: new 'carers grant' funding to local authorities; legislation providing carers with new rights and entitlements; and new support services for carers (Clements, 2010; Fry *et al.*, 2009). This enhanced support for carers was developed in the context of an overall policy approach designed to deliver wider changes in the English health and social care system, in which the emphasis was on 'personalised' support, greater independence, dignity and choice (for carers and those they support), and more control for service users, through the use of direct payments and personal budgets. New legislation directly addressing carers' needs included the *Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004*, both of which strengthened policy on Carer's Assessments. Other developments involved a sharpened focus on supporting carers to remain in or return to work (addressed in the *Work and Families Act 2006*) and increased pension protection for carers (in the *Pensions Act 2007*). In 2007, the then Prime Minister announced a *New Deal for Carers*, promising an increased emphasis on breaks and other social care

support for carers. The importance of addressing carers' needs in the health system was acknowledged in the DH White Paper *Our Health, Our Care, Our Say* (2006), the Darzi review (Darzi, 2009) and the NHS Constitution (Department of Health, 2010d). During this period the development of support for carers was monitored by the Commission for Social Care Inspection, whose annual reports provided a picture of how local authority services to carers were developing (CSCI, 2007, 2008, 2009). A Standing Commission on Carers was also established. The importance of responding to carers' needs and the crucial contribution carers make to the sustainability of the health and social care system were thus acknowledged across the political spectrum in the 2000s. At the local level, many local authorities used their DH carers' grant funding to develop local carers' strategies and appoint 'carers' lead officers' to champion change (Fry *et al.*, 2009). While supporting carers often involved local authorities and voluntary agencies working closely together, and some local authorities engaged very actively with carers in developing their plans and services, effective partnership working across the statutory health and social care sector was less widespread.

Following the New Deal for Carers announced in 2007, a revised National Carers' Strategy in 2008 set out the then government's short-term agenda and long-term vision for the future support of carers. The short-term commitments included funding planned short breaks for carers, piloting annual health checks for carers to help them stay well and introducing training for GPs and other NHS professionals to help them recognise and support carers. The need to secure a more significant role for the NHS in supporting carers and opportunities for achieving better outcomes for carers through more integrated and personalised NHS support were also identified. It was against this policy background that the DH established the DS programme in 2008-9, choosing this as a way of using the new investment to increase the evidence base about carer support as well as to:

> *'meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen.*
> *(DH, 2009:5)*

The policy landscape affecting carers saw further change during the implementation of the DS programme. After the financial turmoil of 2008, it became clear that central government budgets would come under additional pressure during the DS delivery period[1]. To address this, the DH decided, a few months after commissioning the DS programme, to shorten its delivery period from 24 to 18 months. The change of government in May 2010 led to further policy developments, with some impact on the implementation of the DS programme. On assuming office, the Conservative-Liberal Democrat Coalition Government quickly pledged to update the National Carers' Strategy and set out its vision for carers for the period 2011 to 2015. This update, published in November 2010, identified four priority areas in support for carers: early identification and recognition of carers; enabling carers to fulfil their educational and employment potential; personalised support for carers and those they care for; and supporting carers to remain mentally and physically well (HMG, 2010:5). The work undertaken in the DS, as this report shows, is relevant to several of these new priority areas and to other changes expected to occur in the health and social care system in the future.

The new government's programme included substantial changes to the NHS and new arrangements affecting the delivery of social care. A Health and Social Care White Paper (July 2010) outlined plans for PCTs to lose their commissioning role and for some of their responsibilities to transfer to local authorities (DH, 2010b)[2]. The Secretary of State for Health announced that PCTs would cease to exist after 2013 and that service commissioning would in future be led by clinical commissioning groups. This had an impact in those DS where PCT staff expected their posts and responsibilities to be affected

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[1] A new Comprehensive Spending Review (CSR) of public expenditure was due to be announced in 2010.
[2] The subsequent Health and Social Care Bill had not completed all its parliamentary stages when this report was written in September 2011.

by the planned changes, in some cases raising issues about the sustainability of the site's activities. In November 2010 a new vision for adult social care was set out emphasising the values of 'freedom, fairness and responsibility' and making a link between social care and the 'Big Society'[3]. Government stressed its commitment to expanding the use of individual budgets and direct payments and its determination to 'break down barriers between health and social care funding' (DH, 2010a). Delivery of DS services was also affected by the timing of the 2010 General Election, which prevented the DH from confirming second year DS funding until after the year two delivery period started. Some sites delayed planned activities, such as marketing, until this funding was confirmed. Staff in some sites felt this affected delivery and outcomes.

1.3   The Demonstrator Sites programme

In February 2009, all English PCTs and local authorities with social service responsibilities were invited to submit Expressions of Interest to be funded as a DS. In appropriate cases, they were then asked to develop bids for DS funding over two years, which could be supplemented by local resources. The DS funding could not replace existing budgets and had to be used to develop additional support for carers (DH, 2009). Three types of site[4] were planned:

- *Breaks for carers:* these aimed to measure the quality and effectiveness (including cost effectiveness) of a range of new approaches to offering breaks to carers.

- *Health and well-being checks for carers:* here the intention was to deliver annual health and / or health and well-being checks for carers.

- *Better NHS support for carers:* these were to explore ways of providing better support for carers in NHS settings.

Twelve breaks, six health checks and seven NHS support bids were awarded DS funding. These 25 successful sites were located in all but one of the nine English regions: East of England (three sites); East Midlands (three sites); London (four sites); North East (two sites); North West (four sites); South East (three sites); South West (five sites); and West Midlands (one site). A good geographical spread was thus achieved, with Yorkshire and the Humber the one region in which no site was located.

Successful applicants for DS funding were notified in spring 2009 and expected to begin operating in autumn 2009. They were notified in June 2009 of the reduced funding period. This did not involve budget reduction but required adjustments to the timing of delivery plans which some sites found difficult. DS service delivery officially started in the final quarter of 2009, although some sites undertook preparatory work in summer 2009. The objectives for the overall DS programme are set out in Box 1.1.

In addition to its planned activities, the DH hoped each Demonstrator Site would undertake a local evaluation of its work (for local planning purposes) and DS funding included resources for this. All sites were also expected to take part in the national evaluation of the programme. The role of the national and local evaluation studies was to monitor and evaluate the three models of support for carers, so that findings about successful outcomes and effective processes in the health and social care sector could be disseminated widely. The DH appointed four Expert Advisers to support the work of the sites and these Advisers also acted as a point of contact between sites and the DH.

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[3]   Government's commitments to support the 'Big Society' featured in the Coalition Agreement (HMG, 2010).
[4]   These are referred to in this report as 'Breaks sites', 'Health Checks sites' and 'NHS Support sites'.

Box 1.1 Objectives of the Demonstrator Sites programme

- Establish demonstrator sites involving: carers and people they support, social care, housing, health, the third sector, the private sector and others to develop improved support for all carers.

- Evaluate effective engagement of carers throughout the planning, delivery and evaluation of each demonstrator site.

- Create an effective learning and support network for the demonstrator sites in order to support their development.

- Establish a rigorous evaluation of the project as a whole, which will add to the current evidence base and identify what benefits can be achieved for all carers in each of the three strands of the project.

- Provide evidence about the effectiveness of specific policies or initiatives to better support all carers.

- Provide any evidence that early investment in supporting carers results in savings later as carer health, and that of the person they support, is maintained or improved.

- Disseminate and share widely the emerging learning as well as a final report from the demonstrator sites to encourage the adoption and dissemination of benefits within the social care, health and wider community.

- Establish a knowledge base to support local authorities and PCTs in their commissioning and performance management of services to support carers and the people they support.

Source: DH (2009).

1.4   Study design

The DH indicated its requirements for the national evaluation study of the Demonstrator Sites programme in an 'Invitation to Tender' issued in spring 2009, and CIRCLE set out a detailed research design in its successful proposal for the work[5]. This report is based on the national evaluation study undertaken by the CIRCLE study team between August 2009 and September 2011. An outline of the study objectives and the main research methods used to achieve them are set out in Table 1.1. The detailed research questions the study sought to address are included in Appendix A.1[6].

The evaluation study used a mixed methods approach comprising analysis of monitoring data, case studies of selected sites, surveys of carers taking part in the DS programme, interviews with staff delivering the programme and documentary analysis. Regular communication was maintained with staff in the DS through a website hosted by the CIRCLE study team and quarterly calls with each site's Evaluation Liaison Officer (ELO). The CIRCLE team also held Contact Events for DS staff in February 2010 and March 2011.

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[5] The main features of the research design were accepted by the DH, with minor modifications, when the study was commissioned.
[6] Appendices to this report are available in a separate electronic document.

Analysis of monitoring data

Preparing standard documentation to monitor the activities of the DS was an early task for the study team[7]. Following discussion with the DH and Expert Advisers, three research instruments were devised, as follows:

* *Baseline Data Statement.* This was used to establish what services / support for carers existed before the DS programme commenced in each site (see Appendix A.2 for research instrument). It was provided by the DS lead partners soon after the programme began. Of the 25 sites, 22 complied with this request.

* *Individual Carer Record* (ICR). To gain an understanding of the characteristics of carers who accessed the DS support, an ICR was designed. This was completed by staff in the sites with carers who consented to providing the information. Site staff then submitted the ICR data (in most cases electronically) to the study team. ICR data was received for over 5,000 carers (27% of carers recorded by sites as having engaged with the DS programme). Collection of this data could only commence when ethical approval and research access procedures had been completed in each site. Return of ICRs was uneven between sites for this and other reasons (see Appendix A.1 for further discussion).

* *Quarterly Reporting Template* (QRT). The QRT was designed to collect information from sites at quarterly intervals about services delivered and taken up, and their costs (see Appendix A.3 for research instrument). Most sites provided all (or almost all) of the QRTs requested.

The analysis of monitoring data was used to map DS provision and to inform the analysis of the cost and effectiveness of the DS activities. It is referred to in Chapters 2, 4 and 6 of the report and detailed data from these sources is used in Tables 5.1, 6.2, 6.4 and 6.6.

Case studies of selected sites delivering the DS programme

Sixteen case studies of selected sites of all site types (Breaks, Health Checks and NHS Support) were carried out, the aims of which were to:

* Capture a holistic picture of how service delivery was organised and gain an understanding of how the activities and partnership arrangements in place affected the staff, organisations and carers involved.

* Clarify the degree of innovation involved, and understand the importance of past experience in successful delivery (to aid judgement about whether service innovations could be replicated elsewhere).

* Compare different models of delivery and service design, and their costs and benefits.

Each case study included one or more site visits, during which selected staff were interviewed and some activities were observed (e.g. site steering group or project board meetings). Case study sites provided more detailed information than other sites about their plans and activities, and were asked to complete some additional research instruments. Case study selection and inclusion criteria, and further details of the approach taken, are provided in Appendix A.1.

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[7] No management information system was in place when the study commenced.

Face-to-face interviews were carried out with a range of different staff as part of the case study visits (see Appendix A.6 for sample interview guide). Interviewees were selected on the basis of a pre-visit questionnaire completed by senior site staff, which specified the job roles of DS staff available during the fieldwork period. Interviewees were identified by the study team, in agreement with sites, to maximise the range of staff roles and partner organisations included in the study. A total of 148 interviews were carried out with site staff during the case study visits.

**Table 1.1 The national evaluation study:
summary of objectives and methods used**

	Monitoring data	Case studies	Survey of carers	Documentary analysis	Staff interviews / survey	Local evaluation studies
Map Demonstrator Sites' activities	✓	–	–	✓	✓	✓
Provide evidence about:						
The effectiveness of specific initiatives	✓	✓	✓	✓	✓	✓
The impact of initiatives on carer health and well-being	–	✓	✓	–	✓	✓
The impact of initiatives on persons cared for	–	–	✓	–	–	✓
The cost of initiatives	✓	✓	–	✓	✓	✓
Carer engagement in planning / delivery / evaluation	–	✓	–	✓	✓	✓

Survey of carers taking part in the DS programme

The perceptions and experiences of carers who accessed the different DS services were captured using structured questionnaires which included some open-ended questions. Selected carers in the Carers' Breaks and Health Checks sites were recruited into wave one of the survey by site staff at the point of, or just after, they received an initial service. Approximately four months after their completed wave one questionnaire was received, consenting carers were sent a follow-up wave two postal questionnaire at their home address.

The wave one questionnaire focused mainly on how carers found out about the service, what support or services they received, and what they thought about the service. It also included questions drawn from a standardised measurement instrument (see Chapter 5). In wave two, the questionnaire asked carers questions about their own health and well-being, quality of life and other aspects of their circumstances and experiences, designed to explore whether they felt the DS support received had enhanced their ability to have 'a life of their own'. The questionnaires used are provided in Appendices A.7 - A.10, while Appendix A.1 explains that two of the twelve Breaks sites used a combined version of the wave one and wave two questionnaires.

Although not part of the original study design, a single questionnaire (without follow-up) was also distributed to carers receiving support in the NHS Support sites. This was similar in content to the wave two Breaks and Health Checks questionnaires[8].

Completed questionnaires were received from a total of 1,008 carers (353 in Breaks' sites, 453 in Health Checks sites and 202 in NHS Support sites). Distribution of the wave one questionnaire was affected by a complex ethical approval process and the need to ensure that carers were not asked to participate in both the national and the local evaluation surveys (which some sites undertook).

Analysis of the survey data was conducted using SPSS with tests of statistical significance applied as appropriate. Data quality was assured through conventional data cleaning and checking techniques. Results from the survey of carers informed the discussion of the outcomes of the DS support for carers (see Chapter 5, in which data from the survey are presented).

Documentary analysis

All sites were asked to supply documents and materials relevant to their DS activities to assist the study team in mapping the range, type, variety, scale and costs of provision. Many sites supplied these using the DS website (see below), and the case study sites often supplied documents during visits by the research team (see above). The documents included: initial DS proposals and delivery plans (and subsequent revisions to these where relevant); budgets and financial reports; marketing materials; operational documents; partnership agreements; minutes of meetings; and local evaluation plans / research instruments. They provided information about delivery relationships and partnerships, local objectives and details of how support and services were provided. All sites provided some documents, in most cases supplying these throughout the delivery period. In total, 1,205 documents were submitted, with the number for each site ranging from ten to 117. All documents received were logged, read, summarised and analysed by the study team, with data recorded in a thematic template for each site (for further details see Appendix A.1).

Staff interviews and surveys

The evaluation team liaised regularly with the DS through a series of *Quarterly (telephone) Calls* with Evaluation Liaison Officers. These calls assisted the study team in maintaining good working relationships with sites, and aimed to gather information to map site activities and capture changes and developments at the local level. Using a topic guide, the study team explored with each site how plans were being implemented and what impact activities were having, as the sites' work progressed (see Appendix A.1, Table A.2). Each call was supported by follow-up email dialogue and exchange of documentation, if appropriate. The quarterly calls, which typically lasted for 30 to 90 minutes, also gave sites the opportunity to ask questions about the national evaluation study. Five rounds of quarterly calls were conducted and the majority of sites took part in each round.

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[8]   It was not originally intended to survey carers in the NHS Support sites, for a range of practical and ethical reasons associated with their expected circumstances at the time of accessing services in this type of site. Returns of this questionnaire in each site were insufficient to justify statistical analysis.

A Key Actor Survey was also developed and distributed. This was a postal questionnaire distributed to selected staff in each site to capture their views and perceptions about: the impact of DS interventions on carers; the costs / cost-effectiveness of site activities, partnership arrangements and implementation; and impacts on staff and their roles (see Appendix A.11 for research instrument). Responses to the Key Actor Survey were received from 61 DS staff, and follow-up telephone interviews were conducted with 15 of these respondents.

At the end of the DS delivery period, telephone interviews were also completed with the Expert Advisers, all of whom co-operated with this aspect of the study. These interviews examined the Expert Adviser's role and their perspectives on the developments, achievements and issues arising in the DS.

Information gathered during quarterly calls, Key Actor Survey interviews and Expert Adviser interviews was recorded in templates enabling data to be retrieved and interrogated during the analysis phase of the study. In this report these data inform, and where relevant, are presented in Chapters 2 to 6.

Review of DS local evaluation reports

The DH expected and recommended that all sites would undertake a local evaluation of the provision developed using the DS funding. The form local evaluation studies would take was not specified, but in site bids all sites committed to writing a local evaluation report[9]. Sites were asked to send these reports to the national evaluation study team in summer 2011, so that any local learning not identified in the national evaluation study could inform this report. All sites submitted a local evaluation report (although some reports were in a draft or incomplete form) and reference is made to these in Chapters 2 and 6 and elsewhere in the report as appropriate.

Additional contact with the sites

At the outset of the evaluation study, the DH asked the evaluation team to develop and maintain a DS programme website[10]. The website was designed for sites to use as an internal forum to share best practice, publicity materials, information documents / packs, models of practice, forms used in delivering activities and to facilitate communication with and among the DS. Use of the website, which was voluntary for sites, was variable. The Breaks sites made most use of this facility, but its use by some NHS Support and Health Checks sites was limited. Most sites supplied many more documents to the national evaluation team than they agreed to share with other sites using the website (Appendix, Table A.1). In total, sites provided 704 documents to be uploaded to the website.

The study team arranged two 'contact events' during the delivery period, to which all sites were invited to send representatives. These provided an opportunity for exchange of information between sites and the study team and a chance to debate emerging issues, compare practice in the sites and reflect on emerging research findings.

Implementation issues

In general, the study was implemented as intended although modifications were made to accommodate: the change to project timescales (24 to 18 months); an extremely complex ethical approval process arising from the NHS Research Ethics Committee's decision in autumn 2009

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[9]   The local evaluation studies were undertaken by each site, which could choose its own study design and methods and whether or not to commission an external evaluator. The national evaluation team was not responsible for the development or implementation of these studies.
[10] A detailed report on the development and use of the DS website can be found in Appendix D.

to treat the study as a 'research' study rather than a 'service evaluation'[11]; and the DH's request that the national evaluation team gather Management Information data and set up and manage the DS website. Completion of ICRs was disappointing in some sites (especially some NHS Support sites) despite considerable efforts by the evaluation team, Expert Advisers and DH staff to increase ICR numbers. Distribution of the questionnaires in the survey of carers was carried out by the sites and was uneven between sites. The study team had no way of calculating survey response rates as it was impossible to know how many of the questionnaires distributed to sites were actually given to carers. These factors are discussed in more detail in Appendix A.

The DH hoped the DS programme would provide good data on the costs and benefits of supporting carers. However the study team was unable to access the data needed to undertake full analysis of costs and benefits, or to calculate displacement or deadweight in the DS programme, as the programme was set up with a high degree of variability in the scale, remit and aims of activities in the different sites, with no control sites in place. This was fully discussed with the DH and its advisers in 2009-10. Key issues for the national evaluation study in assessing costs and benefits, also reported in many of the local evaluation reports, included that the DS funding:

- Was not 'ring-fenced' for exclusive use on DS activities.

- May not have been the full or only cost of developing and delivering the activities.

- Could not be linked to specific services, or aspects of services, by site staff.

- Was variably allocated to and needed for initial project set-up costs.

In addition:

- Site targets varied and some local plans were unclear about target outcomes or specified these in general terms, making comparison of 'costs per carer supported' difficult.

- Some sites lacked adequate baseline information.

- Isolating the specific impact of the DS funding was difficult or impossible in many cases.

- Sites chose their own definition of outputs, and the way they measured outputs varied.

- Beneficial outcomes from the DS activities might not be realised during the study period, or might arise in other parts of the health and social care system.

- Eighteen months is a short period in which to identify and measure impacts of carer support on the wider health and social care system.

The costs and value implications of the DS activities are discussed in Chapter 6, which draws on the evidence available, including that supplied in the local evaluation reports.

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[11] The complexity of this process and its impact for the study were fully outlined in evidence to the Rawlins Review of health research regulation and governance in the UK submitted in 2010.

1.5   Structure of the report

The remainder of this report is organised as follows:

• Chapter 2 maps the activity of each of the three types of Demonstrator Site, also indicating, as far as possible, the range and type of activities developed in the individual sites. It develops a typology of DS provision which is referred to throughout the following chapters of the report.

• Chapter 3 explores the partnerships developed to deliver the DS services, and highlights the learning from these concerning staffing, impacts on workload and professional roles and implications for carers' services.

• Chapter 4 provides evidence of how sites approached the task of engaging and supporting a wider group of carers, and comments on how effective the different approaches were. The chapter includes an overview of the marketing tools and techniques used by the DS and of the extent to which carers were involved in the planning and evaluation of services.

• Chapter 5 summarises which carers engaged with the DS services and what carers valued about, and appeared to gain from, the support they received. It draws on the study's survey of carers to explore the impact of the three types of service / support on carers and reports on what DS staff viewed as the main benefits for carers.

• Chapter 6 discusses the costs and benefits of the services and activities the DS provided, drawing on evidence available from monitoring data, staff perceptions of benefits and risks avoided, and case study examples, and on the DS local evaluation reports where appropriate.

• Chapter 7 reflects on the activities and outcomes of the DS, considers the implications of the DS programme for building carer services in the future and presents the conclusions and policy recommendations of the national evaluation study.

• Appendices to the report include:

    Appendix A: Study research instruments and other information about the evaluation.

    Appendix B: A profile of the main activities and characteristics of each of the 25 sites.

    Appendix C: Additional data on site partnerships and data derived from ICRs on carers who participated in the DS.

    Appendix D: Report on the DS website and its use by the study team and DS staff.

Chapter 2
Supporting Carers' Health and Well-being through Innovative Approaches

Viktoria Joynes with Christina Buse, Andrea Wigfield and Sue Yeandle

2.1   Introduction

Mapping the activities and achievements of the Demonstrator Sites was a key objective of the national evaluation. Over 18 months, the 25 sites planned and delivered a large volume of services (including providing support to 18,653 carers). This chapter describes the different approaches that each of the three types of site (Breaks, Health Checks and NHS Support) took and outlines the key activities that were involved. In planning and delivering their provision, sites were guided by the outline specification provided in the prospectus for the Demonstrator Sites.

The chapter presents the available information about the sites' activities by each type of site in turn. Within each, staff explored different approaches for carer support and service delivery, with different resources and in different contexts. All sites were evaluated against their own, sometimes very different, aims and objectives, but it was never the intention of the national evaluation study to compare directly the performance of one site with another, nor has this been attempted. The chapter maps site activity, presenting information about the nature of the services delivered, noting how services were provided and by whom. It explores innovation in site delivery, the role of the partner organisations (a more detailed discussion of which is presented in Chapter 3), the flexibility in the provision, and challenges encountered by the sites. Information drawn on in the chapter is derived from: the national evaluation team's quarterly calls with site staff; material from the sites selected as case studies; documents supplied by all sites; and data derived from the management information collected (in the Individual Carer Records, baseline statements provided by sites and in their quarterly reports to the DH).

In mapping what the 25 Demonstrator Sites achieved during their 18 months of operation, the chapter forms the backdrop to the topics discussed in subsequent chapters: partnership, professional roles and care co-ordination (Chapter 3); carer involvement and engagement (Chapter 4); carers' own responses to the enhanced support they received (Chapter 5); and the costs and benefits of the provision (Chapter 6).

Within this chapter, section 2.2 focuses on the Breaks sites and explores the extent to which sites succeeded in developing innovative and flexible breaks provision through the services they provided and the way carers were supported to access them.

The specification for the Breaks sites had invited bidders to develop models of breaks provision that would *'demonstrate the effectiveness, including cost-effectiveness, of breaks and help identify what constitutes high quality provision based on carers' needs'* (DH, 2009:15). It had also reminded bidders that the 2008 National Carers' Strategy had highlighted *'major gaps in the evidence'* about the best and most cost-effective way to provide breaks for carers (HMG, 2008:74). The specification listed a series of possible *'innovative and personalised'* approaches to breaks provision which sites might consider exploring, pointing out:

> *Evidence suggests that an effective break for a carer is unlikely to be achieved unless a holistic / whole family approach is taken. We also know that unless replacement support is reliable and of high quality, carers will not take or benefit from breaks.*
>
> *(DH, 2009:15)*

The activities of the Health Checks sites (which experimented with a range of ways of offering and checking carers' health and well-being) are discussed in section 2.3. Particular attention is paid to variation in the way the health and well-being checks were delivered and to how flexible the arrangements were. The specification for bids to provide physical health, and health and well-being checks for carers had noted that carers often have health-related problems related to their caring roles, and that emotional health problems can be caused and exacerbated by the stress of caring for someone. It stated that:

> *Carers should not have to ignore personal health concerns and needs because their caring role does not allow time to address them. The services and support available to carers should be such as to enable them to stay as mentally and physically well as possible throughout their caring role.*   *(DH, 2009:20)*

Section 2.4 explains how the NHS Support sites adapted and extended services for carers in NHS settings, in some cases developing entirely new provision. In these sites the expectation had been that better outcomes for carers and those they care for could be achieved if improved arrangements were made to:

> *Involve carers in diagnosis, care and discharge planning, provide support for carers at GP surgeries and in mental health and acute trusts, as well as providing flexible support for carers across all support agencies.*   *(DH, 2009:24)*

Here too, the DH hoped the work undertaken in the sites would contribute to a stronger evidence base about effective ways of supporting carers in the health system, and would help meet one of the commitments set out by government in the 2008 National Carers' Strategy:

> *By 2018 carers will be respected as expert partners and will have access to the integrated and personalised services they need to support them in their caring role.*
>   *(HMG, 2008:16)*

The performance of the 25 sites, in terms of innovation and the achievement of each site's own aims and objectives, is assessed in this chapter based on the full range of available data, including information provided by sites, data collected using the research methods described in Chapter 1, and (where possible) in the local evaluation reports prepared or commissioned by individual sites. Many sites found it necessary to modify or adjust their initial plans during the delivery period, which lasted for 18 months. Some changes were made in response to interim evidence collected or on the advice of the External Advisers or the DH; others were made in response to local circumstances or to advice received locally.

A brief section drawing on the local evaluation reports available for consideration by the national evaluation team in July and August 2011 is provided in section 2.5. This does not attempt to summarise their findings, but notes the methods they employed, including the extent to which they were able to explore the costs and benefits of local services. Where it adds necessary information, evidence from these reports is referred to throughout the chapter and elsewhere in this report.

The chapter concludes (section 2.6) with a summary of the key findings emerging from this mapping exercise. The assessment of performance against objectives is an essential part of any evaluation study, but has been especially difficult here because of the wide variations between sites' plans, budgets, previous experience and local contexts. Given their remit to demonstrate new or better ways of providing support to carers, sites have been assessed against the extent to which their plans and activities were innovative, as well as against the targets and aims they set themselves (in dialogue with the DH) for numbers of carers supported and targeting 'under-reached' carers (discussed in Chapter 4). Initial aims and targets were sometimes re-negotiated and were not always specific or detailed in the first place. Chapters 3, 4 and 5 in the report consider the evidence about how and why specific aspects of the work sites undertook did or did not work and Chapter 6 explores the costs and benefits of the

provision. Inevitably, some of the more ambitious plans sites set out could not be fully achieved, while more modest aims were sometimes readily met. Throughout the study (which brought the national evaluation team into contact with many staff in the sites at different levels and in different organisations) the commitment and enthusiasm shown by those delivering the DS activities was striking, and in most sites great efforts were made to overcome difficulties or make innovations work. The evaluation team's recommendations about which types of support were successfully developed, and thus offer examples or guidance on how support for carers might be developed in other localities in the future, are presented in Chapter 7.

2.2   Carers' Breaks sites

The emphasis on innovation in the DS programme was based on pushing the personalisation agenda forward and developing tailored breaks and services. This allowed each of the Breaks sites[12] to develop its own definition of a 'break' and encouraged sites to involve carers in making that decision'[13]. The 12 Breaks sites outlined a series of objectives for their activities which included developing, or making changes in, breaks provision which could:

• Improve carers' health or well-being (ten sites).

• Increase or widen access to breaks (eight sites).

• Widen the range of breaks available and / or tailor the breaks to the needs of carers (seven sites).

• Increase choice and control for carers (seven sites).

• Improve carers' quality of life (six sites).[14]

Carers' Breaks delivery: models and approaches

Having been guided to develop new breaks services to respond to the individual needs of carers in a flexible way, Breaks sites all developed their own models of what a 'break' would look like or consist of. Four main approaches to breaks provision were offered by the sites (some adopted just one of these approaches and others more than one): specialised short-term respite for carers of people with dementia / mental ill-health; alternative care in the home; personalised breaks (whereby carers defined what a break meant to them and were able to select a break of their choice); and new ways of accessing breaks for carers. The sites themselves did not directly provide the personalised breaks but provided funding for the breaks either by directly paying providers for services or through direct payments to carers or carers' personal budgets. As can be seen from Table 2.1 the personalised breaks can be categorised into eight main types: carers' holiday breaks; practical help in everyday life; well-being support / services; training for the caring role; work-related training; training for other skills; and funding for the purchase of equipment and domestic goods (for a more detailed summary of the support and activities offered in each site see Appendix B).

The majority of the sites (11/12) offered alternative care in the home, provided by support workers or volunteers, which was particularly targeted at co-resident carers who were unable to leave the person they care for unattended (Table 2.1). This was sometimes offered as a means of enabling the carer to access other activities, or could count as a break in its own right.

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[12] In this chapter, and elsewhere when discussing areas of good or effective practice, sites are usually referred to by their site name. In some later chapters, where data is drawn from case study interviews with staff, individual sites are not named to ensure views (and any quotation from interviews) are not attributable to individuals.

[13] Examples and the implications of carer involvement are discussed in Chapter 4.

[14] Appendix B indicates the objectives and delivery aims of each site.

Many sites (9/12) offered some form of personalised break. This often included a one-off payment to carers to help with the costs of a holiday break, which could vary from a day trip to a two week holiday, or payments to enable carers to attend activities or courses designed to improve their well-being, such as alternative therapies, gym memberships, or stress management courses. Over half the sites (Bath and NE Somerset, Bristol, Lewisham, Liverpool, Suffolk, Sunderland and Torbay) offered a personalised break by providing a 'one-off' payment for the purchase of equipment or domestic goods that enabled the carer to carry out an activity beyond their caring role (for example a laptop for social networking, or a bike to provide a leisure break) and three of these sites (Bristol, Lewisham and Suffolk) also offered 'one-off' or regular payments to help with the costs of support with practical activities in the home such as gardening, cleaning, shopping and home repairs. The latter type of personalised breaks provision was designed to free up some time for carers who spend large amounts of time caring.

Other sites (Bath and NE Somerset, Bristol, Lewisham, Liverpool, Suffolk, Sunderland) offered various kinds of training to carers as a mechanism for offering personalised breaks including: training for the caring role, such as Caring with Confidence[15]; work-related training for carers wishing to return to, or remain in, paid work; and training for other skills (including for leisure or to support personal development such as driving lessons, pottery classes or massage training).

Two sites (East Sussex and Nottinghamshire) offered specialised short-term respite care[16] for carers of people with dementia / mental ill-health (sometimes provided by partner organisations), through which carer support workers provided activities for the persons being cared for, thereby enabling the carer to have a break from their caring role. As well as offering a varied range of breaks, some sites used the DS funding partly or exclusively to introduce new ways of making breaks accessible to carers[17] (Table 2.1). These included methods to widen access to carers who may have reservations about participating in a Carer's Assessment[18], including alternative ways of accessing a break without a Carer's Assessment (completing a 'membership' form, Bath and NE Somerset; inviting carers to apply to a multi-agency panel, Sunderland, Liverpool; and completing a questionnaire, Suffolk) and alternative ways of having a Carer's Assessment (for example, completing a self-assessment form which is submitted for authorisation, Liverpool, Torbay). Ways of improving access also included approaches which enabled breaks to be flexibly booked at a time / place convenient to carers through on-line booking systems (Derby, Hertfordshire, Warwickshire). An additional method of accessing breaks offered in one site was a prescription of breaks following a carer health check (Bristol), which demonstrated creative working between PCTs and local authorities to provide breaks. The importance to the health and social care system of this type of cross sector working has been noted elsewhere (PRTC, 2011).

Some sites also conducted work with families in developing breaks and services, for example; work with the families of older carers to improve support in Torbay; a 'whole family' service involving intensive work with twelve families in Bristol which aimed to provide more joined up service provision for adults and young people; and providing breaks tailored for the whole family in Suffolk. Other sites offered breaks that were accessed by the carer and person being cared for 'together' (such as meals out with the person cared for or with friends or family, as offered in the Sunderland, Bristol and Suffolk sites). Two Breaks sites (Bristol and Torbay) offered health checks to carers in addition to the breaks provision.

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[15] Caring with Confidence was a government-funded training course designed to support unpaid carers in their caring roles, delivered by selected organisations across England from 2008 to 2010. Caring with Confidence training was delivered by some sites alongside the DS programme, with the DS staff referring carers to the training where relevant. Other sites adapted the Caring with Confidence training materials after the original programme ended, adding more references and signposting carers to local services.

[16] 'Respite care' is the term widely used in social care to refer to short term, temporary care provided (on a planned or emergency basis) in another setting (e.g. a hospital, nursing or residential home or specialist residential facility) for a sick or disabled person so that the (unpaid) person who normally cares for them can have a rest or break from their caring role.

[17] In the Hertfordshire site, for example, the DS funding was used to develop an online booking process, while the cost of the breaks carers booked through this new system continued to be resourced from local authority resources.

[18] Conducting a Carers' Assessment (of a carer's needs) in appropriate cases is a statutory obligation on local authorities. See Clements (2011) for a full discussion.

Table 2.1 Carers' Breaks Sites: main features and rationale of breaks provision

Approach to Breaks provision[1]	Main features	Rationale	Innovation, enhancement or extension to service / support	Sites offering service / support
(A) Specialised short-term respite for carers of people with dementia / mental ill health	Carer support workers engaged people with dementia / mental ill-health in tailored activities in the community or in day-centres on a regular basis (e.g. once or twice a week), enabling the carer to take a break from their caring role.	Carers of people with dementia may find it difficult to leave the person they care for unattended, and to find appropriate day care services. By engaging the cared for person and building relationships of trust over time, this service enabled the carer to feel confident enough to take a break from their caring role.	Extension (East Sussex). Not stated (Nottinghamshire).	East Sussex; Nottinghamshire.
(B) Alternative care in the home	Support workers or volunteer 'sitters' provided alternative care for the person cared for in their own home, enabling the carer to have a break from their caring role.	Co-resident carers who provide extensive support are often unable to leave the person cared for unattended and therefore do not get a break from their caring role. By providing alternative care for the person cared for inside the home, the carer is able to have time for themselves.	Extension (majority of sites). Enhancement (Hertfordshire, Warwickshire).	Bath and NE Somerset; Bristol; Derby; Hertfordshire; Lewisham; Liverpool; Nottinghamshire; Suffolk; Sunderland; Torbay; Warwickshire.
C) Carers' holiday breaks: funding or facilitation	One-off payments to help with / cover costs of a holiday break for the carer, ranging from day trips to two week holidays. Holiday breaks could be taken with or without the person cared for, individually or with friends / family.	Carers with an extensive caring role are often unable to take time out for leisure or relaxation, which can impact negatively on health and well-being. Having a holiday break can provide a 'change of scene' and a chance to relax, with or without the cared-for person, sustaining the caring role.	Enhancement (Bristol, Liverpool). Innovation (Derby, Suffolk). Not stated (Lewisham, Nottinghamshire).	Bristol; Bath and NE Somerset; Derby; Lewisham; Liverpool; Nottinghamshire; Suffolk; Sunderland.
(D) Practical help in everyday life	One-off or series of payments for activities or courses offered to improve carers' well-being, including: alternative therapies; gym memberships; stress management; and 'pampering' sessions. Sometimes offered in conjunction with alternative care.	People caring for a high number of hours per week may neglect their own health and well-being. These services provide an opportunity for carers to look after their own health or well-being needs, or relax away from their caring role.	Innovation (Suffolk). Not stated (Lewisham, Bristol).	Lewisham; Suffolk; Bristol.
(E) Well-being support / services	One-off or series of payments for activities or courses offered to improve carers' well-being, including: alternative therapies; gym memberships; stress management; and 'pampering' sessions. Sometimes offered in conjunction with alternative care.	People caring for a high number of hours per week may neglect their own health and well-being. These services provide an opportunity for carers to look after their own health or well-being needs, or relax away from their caring role.	Extension (Bath and NE Somerset). Enhancement (Sunderland). Innovation (Bristol, Derby, Liverpool, Suffolk). Not stated (Lewisham).	Bath and NE Somerset; Bristol; Derby; Lewisham; Liverpool; Suffolk; Sunderland, Torbay.

[1] Items C–I are categories of personalised breaks selected by carers. The support was usually provided through direct payments / personal budgets / payment to a provider for the cost of the activity.

Table 2.1 Carers' Breaks Sites: main features and rationale of breaks provision (continued)

Approach to Breaks provision	Main features	Rationale	Innovation, enhancement or extension to service / support	Sites offering service / support
(F) Training for the caring role	Carers were referred to or given access to training courses to assist them with their caring role e.g. lifting and handling of the person cared for, Caring with Confidence. Sometimes offered in conjunction with alternative care.	Carers sometimes lack confidence in their caring role, or require support and advice. These courses offered support with the caring role to help carers feel better able to cope, thereby sustaining their caring role for longer.	Extension (Bath and NE Somerset). Enhancement (Sunderland). Innovation (Suffolk). Not stated (Bristol).	Bath and NE Somerset; Bristol; Suffolk; Sunderland.
(G) Work-related training	Carers were referred to or given access to courses to assist them with work-related training, e.g. computer courses. Sometimes offered in conjunction with alternative care.	Carers sometimes report a loss of confidence / skills following time out of employment. Being unable to leave the cared for person unattended makes working difficult. Work-related training and provision of alternative care enables carers to improve their skills and access employment opportunities.	Extension (Bath and NE Somerset). Enhancement (Sunderland). Innovation (Suffolk). Not stated (Bristol, Lewisham).	Bath and NE Somerset; Bristol; Lewisham; Suffolk; Sunderland.
(H) Training for other skills	Carers were referred to / given access to training courses of their choice for personal development or leisure, e.g. driving lessons, pottery courses, massage training. Sometimes offered in conjunction with alternative care.	People who provide a high level of care may find it challenging to make time for self-development and leisure. This training offered carers the opportunity to learn new skills, for leisure and relaxation.	Extension (Bath and NE Somerset). Enhancement (Sunderland). Innovation (Liverpool, Suffolk). Not stated (Bristol).	Bath and NE Somerset; Bristol; Liverpool; Suffolk; Sunderland.
(I) Equipment and domestic goods funding	One-off payment – given for the purchase of items that enabled carers to get a break, e.g. a laptop facilitating social networking; a bike or art equipment; equipment to assist with and ease the caring role enabling the carer to take more time for themselves.	The activities which a carer may experience as a 'break' are highly personalised, and may not involve 'traditional' break options, or time away from the person cared for. The purchase of equipment or domestic goods was used to enable the carer to take a personalised break of their choice, at a time and place which suited them.	Extension (Bath and NE Somerset). Innovation (Liverpool, Suffolk). Unknown (Bristol, Lewisham).	Bath and NE Somerset; Bristol; Lewisham; Liverpool; Suffolk; Sunderland; Torbay.
(J) Improving access to breaks	New ways of accessing breaks provided through: • Online booking service. • Access without a Carer's Assessment (e.g. application to decision-making 'panel'; completion of a 'membership form'; via voluntary sector workers). • Self assessment. • Breaks 'prescribed' following health checks in GP practices	Some carers are reluctant to access breaks services through traditional channels (e.g. local authority Carer's Assessments). These initiatives offered more flexible and convenient ways to book a break without going through statutory services.	Innovation (all sites).	Online booking service (Derby, Hertfordshire, Warwickshire). Access without assessment (Bath and NE Somerset, Bristol, Suffolk, Sunderland). Self assessment (Liverpool, Torbay). Breaks 'prescribed' by GPs (Bristol).

Sources: baseline statements, case study interviews, local evaluation reports, quarterly calls, QRTs, site documents.

All sites delivering personalised breaks employed workers (including development workers, brokerage officers, and / or facilitators) to assist carers in selecting the most appropriate break. Most also provided (or signposted carers to) further assistance, often to agencies or organisations with whom they were partners (Table 2.2). Many sites offering personalised breaks also offered funding for 'alternative' care to enable carers to participate in their chosen activities (see Chapter 4). In the Bristol and Bath and NE Somerset sites very few carers opted to use this alternative care[19]. Staff interviewed in these sites reported that the flexibility of personalised breaks enabled some carers to arrange alternative care informally (with friends or family) and claimed that many preferred to do this.

The additional non-staff resources required by the sites varied according to the approaches adopted but (as can be seen from Table 2.2) requirements for sites offering personalised breaks included: a budget and corresponding system for the allocation of direct payments, personal budgets or payment for services; in the sites offering training, venues were often required; and where specialised short term respite was offered, transport and venues were required for the people being cared for.

Innovation in breaks provision

One of the essential criteria for all DS bids was that applicants needed to demonstrate *'innovative approaches that will develop effective future ways of working which will increase choice and control for carers'* and *'build and develop existing [good] practice'* (DH, 2009:9-10). Many innovative approaches were explored in the Breaks sites (Table 2.1) and most of the 12 sites were innovative in some way. Breaks provision considered to be 'innovative' included allocating resources to offer carers ongoing support by paying fees for well-being support or services (for courses, activities, treatments or therapies) in both the Bristol and Derby sites, or to cover the costs of equipment or services which would give carers ongoing practical support (in the Liverpool and Suffolk sites). Holiday breaks were innovative in certain localities, for example in the Derby and Suffolk sites. Training for the caring role, to assist carers to return to or remain in paid employment and for other skills, was also innovative in Suffolk (and Liverpool for the latter type of training). A summary of the key innovative approaches adopted by the sites is provided in Box 2.1.

Delivering breaks through partnerships

To deliver their services and support, Breaks sites formed partnerships with a wide range of organisations. In all but one of these sites the 'lead' organisation was a local authority and most (9/12) also partnered with both a Primary Care Trust (PCT) and one or more local carers' organisations (Appendix C, Table C.1). This collaborative working between PCTs, carers' organisations and local authorities for the delivery of budgets and breaks to carers is recognised as an important factor in successful health and social care services (PRTC, 2011). Some sites included a wide range of voluntary sector organisations in their partnership and / or made informal arrangements with local businesses or agencies (partnerships are discussed in Chapter 3). Sites developed different approaches to working with partner agencies, and some of the roles of the partners involved are shown in Table 2.2. Arrangements varied according to the approach to breaks provision taken by different sites.

Adopting a flexible approach to breaks provision

Demand for the different types of breaks services was high in many of the sites, as indicated in Table 2.2, with demand sometimes exceeding either target numbers and / or capacity (for example for specialised short-term respite in East Sussex; for alternative care in the home in Hertfordshire and Lewisham; for carers' holiday breaks in Bristol; for well-being services in Derby; for return to work IT courses in Suffolk; and for equipment and domestic goods funding in Bristol).

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[19] Take-up of alternative care, or of offers of funding for alternative care, was reported as 'low' in most Breaks sites; sites did not provide details of any systematic monitoring of how this was offered.

Table 2.2 Carers' Breaks Sites: resources, partners and main carer beneficiaries

Approach to breaks provision[1]	Staff resources needed	Other (non-staff) resources needed[2]	Partners' roles	Main carer beneficiaries	Any evidence of demand for service / support
(A) Specialised short-term respite	• Carer support workers or care workers specialising in dementia to deliver respite care. • Line management of carer support workers / management of service.	• Transport service to enable person cared for to attend activities. • Venue for group activities for person cared for.	• Local authority: employed and managed carer support workers (East Sussex), overall management of projects. • Voluntary sector organisations: provided venues / activities / services for person cared for.	Co-resident carers of people with dementia.	• Target numbers exceeded in East Sussex. New staff / agencies were trained to meet demand.
(B) Alternative care in the home	• Care workers to provide alternative care. • Volunteers to provide sitting service. • Volunteer service co-ordinators. • Training and support for volunteers.	• Budget for alternative care. • Systems in place for the allocation of payments / personal budgets. • Transport for care workers. • Checks (e.g. CRB) of all providers of alternative care. • Training venue for volunteers.	• Local authority: managed and oversaw services (majority of sites). • PCT: provided alternative care (Sunderland). • Voluntary sector organisations: provided alternative care (majority of sites), organised volunteer 'sitting' service (Hertfordshire).	Co-resident carers who cannot leave the person cared for unattended.	• Service opened up to more carers to meet demand (Herts). • Demand for service exceeded capacity in Lewisham, leading to delays in direct payments and difficulty finding enough suitable care workers.
(C) Carers' holiday breaks funding	• Development workers / brokerage officer / facilitators to help carers access personalised breaks, choose the 'right' break (which could be a holiday) and plan arrangements, including alternative care. • Management of budgets / service.	• Budget for personalised breaks. • Systems in place for the allocation of direct payments / personal budgets. • Up to date information on holiday break options available.	• Local authorities: employed staff to facilitate breaks; managed and distributed payments; managed and oversaw services (majority of sites). • PCT: provided alternative care (Sunderland). • Voluntary sector organisations: employed workers to facilitate breaks; distributed payments for holiday breaks (some sites); organised or developed holiday breaks (Suffolk); provided alternative care. • Local tourist board contracted as a broker (Liverpool).	Carers with an extensive / long term caring role in need of a holiday break.	• Target numbers exceeded (Bristol). • Holiday breaks reported by staff to be the type of break chosen by the highest number of carers (Bristol, Suffolk).
(D) Practical help in everyday life	• Development workers / brokerage officer / facilitators to help carers access personalised breaks, choose the 'right' break (which could be practical help) and arrange the service. • Staff to provide practical help. • Management of budget / service.	• Budget for personalised breaks. • Systems in place for the allocation of payments / personal budgets. • Up to date information on available services.	• Local authority: employed staff to facilitate breaks; managed / distributed payments for practical help; managed and oversaw services (majority of sites); employed staff to provide practical help. • Voluntary sector: employed workers to facilitate breaks; distributed payments (some sites); provided practical help. • Commercial agencies: provided practical help	Carers providing a high level of care who are unable to find time for practical tasks.	• Staff reported a significant number of carers who chose practical support as their break (Suffolk, Bristol).
(E) Well-being support / services	• Development workers / brokerage officer / facilitators to match services to carers' needs and where appropriate to arrange alternative care. • Therapists, masseurs, personal trainers to provide well-being services. • Management of budgets / service. • Staff to provide alternative care.	• Budget for personalised breaks. • Systems in place for the allocation of payments / personal budgets. • Venues for well-being services. • Up to date information on available services.	• NHS partners: provided well-being services (majority of sites). • Local authorities: employed staff to facilitate breaks; managed / distributed payments for well-being services; managed and oversaw services (majority of sites); provided well-being services (several sites). • Voluntary sector organisations: employed workers to facilitate breaks; distribute payments (some sites); provided well-being services (several sites); provided alternative care.	Carers of people with long-term conditions, especially those who have neglected their own health.	• Targets for well-being services exceeded, difficulties meeting demand (Derby). • Low take up of art and music therapies (Bath and NE Somerset).

[1] Items C–I are categories of personalised breaks selected by carers. Support was usually provided through direct payments / personal budgets / payment to a provider for the cost of the activity.

[2] Services also require marketing materials / publicity.

Table 2.2 Carers' Breaks Sites: resources, partners and main carer beneficiaries (continued)

Approach to breaks provision	Staff resources needed	Other (non-staff) resources needed[2]	Partners' roles	Main carer beneficiaries	Any evidence of demand for service / support
(F) Training for the caring role	• Development workers / brokerage officer / facilitators to match available courses to carers' needs and where appropriate arrange alternative care. • Staff to provide training to carers at flexible times (internally or externally). • Staff to provide alternative care.	• Budget for personalised breaks. • Systems in place for the allocation of payments / personal budgets. • Appropriate venue and equipment for training.	• Voluntary sector partners: employed workers to facilitate breaks; distributed payments (some sites); provided training; provided alternative care. • Education sector partners: provided training.	Carers who feel they would benefit from such training.	13,939 carers registered with the Caring with Confidence programme, with 10,238 of these attending at least one module.
(G) Work-related training	• Development workers / brokerage officer / facilitators to match available courses to carers' needs and where appropriate arrange alternative care. • Staff to provide training to carers at flexible times (either internally or externally). • Staff to provide alternative care.	• Budget for the provision of personalised breaks. • Systems in place for the allocation of payments / personal budgets. • Appropriate venue and equipment for training.	• Local authority: distributed payments; provided training (Lewisham). • Voluntary sector partners: employed workers to facilitate breaks; distributed payments; provided training; provided alternative care. • Education sector partners: provided training.	Carers of working age who want to improve their skills and employment prospects.	• Carers' computer courses fully booked in an hour (Suffolk).
(H)Training for other skills	• Development workers / brokerage officer / facilitators to match available courses to carers' needs and where appropriate arrange alternative care. • Staff to provide training to carers at flexible times (internally or externally). • Staff to provide alternative care.	• Budget for personalised breaks. • Systems in place for the allocation of payments / personal budgets.	• Voluntary sector partners: employed workers to facilitate breaks; distributed payments; provided training; provided alternative care. • Education sector partners: provided training.	Carers who want to learn new skills / have time for their own leisure and self-development.	• No information supplied.
(I) Equipment and domestic goods funding	• Development workers / brokerage officer / facilitators to help carers to access personalised breaks (which may be equipment) and explore what can be bought on behalf of the carer.	• Budget for personalised breaks. • Systems in place for the allocation of payments / personal budgets. • System in place to establish who is responsible for equipment, e.g. through warranty. • Training / support for carers who need assistance using equipment.	• Local authorities: employed staff to facilitate breaks; managed / distributed payments for equipment; managed and oversaw services (majority of sites). • Voluntary sector organisations: employed workers to facilitate breaks; managed payment for equipment (Suffolk and Torbay).	Carers who wish to have a personalised break which does not necessarily involve time away from the cared for person.	• Target numbers exceeded (Bristol).
(J) Improving access to breaks	• Technical staff to build and maintain website. • Staff to train carers / service providers in website use. • Staff on multi-agency panel to make decisions regarding breaks allocation. • Break facilitators / support workers to help carers access breaks without assessment. • Staff to co-ordinate self assessment process.	• Website: ability to host website either as a stand-alone site or as pages on an existing website (e.g. a local authority website) and agreement with hosting organisation about responsibility for technical support and website maintenance. • Venue for panel meetings. • Self assessment: forms and submission procedures.	• NHS partners: provided well-being services (majority of sites). • Local authorities: employed staff to facilitate breaks; managed / distributed payments for well-being services; managed and oversaw services (majority of sites); provided well-being services (several sites). • Voluntary sector organisations: employed workers to facilitate breaks; distribute payments (some sites); provided well-being services (several sites); provided alternative care.	Carers who do not access statutory services due to the time constraints of caring, or reluctance to use / approach statutory services.	• Service opened up to more carers to meet demand (Herts). • Positive feedback regarding self-assessment forms (Liverpool). • Target numbers exceeded (Bristol). • Additional workers needed to meet demand (Torbay). • Increased staff workloads due to demand (Sunderland).

Sources: case study interviews, local evaluation reports, quarterly calls, QRTs, site documents. Notes: Services also require marketing materials and publicity.

Box 2.1 Carers' Breaks: key innovations adopted by sites

- New ways of providing information and advice (Derby and Hertfordshire).

- Support with practical activities in the home (Suffolk).

- One-off payments for equipment and domestic goods (Liverpool and Suffolk).

- Training for carers covering the caring role and work-related (or other) skills (Suffolk).

- New ways of communicating with, or providing services to, carers using on-line breaks booking systems or carer websites (Hertfordshire, Warwickshire, Suffolk).

- Introducing carer self-assessment (new in the Liverpool site).

Sources: baseline statements, case study interviews, local evaluation reports, quarterly calls, QRTs, site documents.

Staff reported that some types of break were much more 'popular' than others[20]. Staff in the Bristol site listed holidays, days out, gym memberships, computers / ICT equipment, white goods and home improvements / practical solutions (along with 'pampering' and alternative therapies, which were also popular options in Sunderland) as the most commonly selected breaks. In the Suffolk site, staff reported that holidays, trips out and home improvements were the most frequently selected options, whilst in the Bath and NE Somerset site, 'educational courses' were popular choices. Demand for holiday breaks and practical solutions was also highlighted in recent research by the Princess Royal Trust for Carers and Crossroads Care, which claimed that carers with an extensive caring role needed time to carry out everyday practical tasks, and valued short, inexpensive holiday breaks to 're-charge their batteries' and improve mental well-being (PRTC, 2011). The Bath and NE Somerset site also explored offering music and art therapies, but found there was less interest in these. Staff nevertheless felt carers who accessed them enjoyed, and appeared to gain a lot from, these services.

Breaks for the carer together with the person they care for were accessed regularly, although in the Nottinghamshire site, staff reported low interest in joint breaks among carers of people with a head injury (one of its target groups), noting that these carers often preferred a break away from the person they cared for.

Sites often made adjustments to services as they became more aware of carers' needs or implementation difficulties. In the Nottinghamshire site, some under-spent funds were re-allocated (with the agreement of the DH) to personalised breaks in cases where the breaks already available were not appropriate to meet the carer's needs. In the Bristol site, demand from carers led to an increase in the provision of particular types of break (e.g. computer skills, photography, arts and crafts and fitness, leisure days). In some sites, further elements were added to delivery and these included adding: an 'end of life' service funded by the local authority to provide breaks for carers (Nottinghamshire); residential short breaks and a volunteer sitting service (Hertfordshire); and a 'finding the balance' course (Bath and NE Somerset).

Challenges in breaks provision

Not all approaches were successful, as was to be expected in a demonstration programme. Ideas and plans which proved especially difficult to implement in some (but not all) Breaks sites included: delivering breaks or other services in partnership (including those with voluntary sector organisations and GPs);

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[20] This is not the same as being able to provide evidence of 'take-up' of a certain type of break, which would have involved records being kept of how many carers were offered which break and which ones they selected. The national evaluation team is not aware that any sites kept detailed records of this kind.

discount card schemes; websites / on-line break bookings systems; and finding carers / providing access to services in rural areas. System responsiveness (in terms of ability to provide a timely and appropriate response to carer needs) initially presented a challenge in several sites, and response to demand for breaks was sometimes delayed due to challenges in implementing new systems, new staffing arrangements and / or limitations on provider capacity to meet demand (discussed in more detail in Chapter 3).

2.3   Health Checks sites

In the six Health Checks sites, the new approaches developed were guided by the aims for carers' health and well-being set out in the 2008 National Carers' Strategy and the specification in the prospectus for Heath Checks site bids. 'Health checks' or 'health and well-being checks' generally involved an examination of the carer's physical health and an exploration of broader well-being factors relevant to each individual carer.

Most Health Checks sites set out their aims and objectives in local documentation and adopted approaches designed to improve carers' health and well-being and to detect conditions or health problems. They aimed to:

• Prevent deterioration in health (all sites).

• Improve access to health and social care services (three sites).

• Improve carers' ability to sustain their caring relationship (two sites).

• Improve carers' ability to manage their own health (two sites).

Health checks delivery: models and approaches

Sites developing health checks provision offered three main types of service: a physical health examination; a well-being check; and ways of both improving and widening access to health checks (as outlined in Table 2.3). All sites offered all types of support, although four sites (Devon, Northumberland, Tower Hamlets and Trafford) offered a combined check, incorporating both physical health and well-being aspects in one check, while the other two (Camden and Redbridge) offered separate physical examinations and well-being checks (for a more detailed summary of the activities offered in each see Appendix B).

The physical health examination was particularly important given evidence that people caring for long hours often neglect their own health needs (Carers UK, 2004). Demonstrator Site staff envisaged that by offering a physical health examination to carers, illnesses would be detected earlier, thereby improving carer health and potentially preventing hospital admission of the carer and / or the person being cared for (see Chapter 6 for more details). The conditions sites screened for in their physical health checks, and the methods used, varied by site and are outlined in Table 2.3. They included: blood pressure; blood sugar / glucose levels; Body Mass Index (BMI); cardiovascular check; cholesterol; current medications / conditions; family medical history; peak expiratory flow-rate; pulse rate; symptoms checklists; and urinalysis through multi-stix. Most sites used nurses to carry out the physical examinations, as shown in Table 2.4, although in the Devon site other clinical support staff and health professionals were used such as pharmacists and health care assistants. In the Trafford site, the checks (which included a combined physical and well-being assessment) were provided entirely by case workers based in the local carers' centre, under the supervision of a nurse assessor. The case workers completed a symptoms checklist with the carer (which was subsequently reviewed by the nurse advisor to identify any issues of concern), but did not conduct any clinical tests (such as blood tests or blood pressure checks). The question of who (what type of worker) should provide the health check, and the competences and professional

Table 2.3 Health Checks Sites: resources, partners and main carer beneficiaries

Approach to health checks provision	Main features	Rationale	Innovation, enhancement or extension to service / support	Sites offering service / support
A) Physical health examination	• Includes examination of: BMI; blood cholesterol; blood sugar; blood pressure; medical history; medication; symptoms checklist (varied by site). • Carried out by: nurses (majority of sites); various healthcare staff including pharmacists and healthcare assistants (Devon); and in Trafford by case workers employed by the local carers' centre.[1]	People caring for long hours frequently neglect their own health (Yeandle et al, 2007a). These services aim to detect illnesses earlier, improve carer health and prevent hospital admission of either the carer or the person cared for.	Innovation (most sites). Extension (Devon). Enhancement (Redbridge).	• All Health Checks sites.
(B) Well-being check	• Includes examination of: emotional / mental health (e.g. using GHQ12, WHO–5)[2] caring situation (e.g. tasks involved in providing care; confidence in caring role; areas where assistance is needed); breaks; life-style; social support; work / education; environment / safety; support needed; finances (varied by site). • Action planning with carers to set out health and well-being goals.[1]	Caring can affect emotional and mental well-being, as well as physical health. These checks offer a holistic approach to carer health within the context of the caring role, and aim to improve carers' mental and emotional well-being.	Innovation (all sites).	• All Health Checks sites.
(C) Accessibility of health checks	• Alternative care to enable carers to attend health checks and other medical appointments. • Widening choice of venue for health and well-being checks, including: health checks for carers in a venue of their own choice (including carers' own homes); checks for ethnic minority carers in community centres; health checks for young carers in sports centres. • Flexible appointment times for health checks (e.g. evenings and weekends).	People with an extensive caring role often lack time to attend medical appointments, and may not be able to leave the person they care for unattended. These services aim to address these barriers and improve access to health checks and medical appointments.	Extension (Northumberland). Enhancement (Devon). Innovation (Trafford). Not stated (Redbridge).	• Alternative care (all sites). • Choice of venue (Northumberland, Redbridge, Trafford). • Tailored options for ethnic minorities and young carers (Devon). • Flexible appointment times (Redbridge, Tower Hamlets).

Sources: baseline statements, case study interviews, local evaluation reports, quarterly calls, QRTs, site documents.
Notes:
[1] All sites examined both health and well-being, either as part of a single health and well-being check (A + B), or as separate checks for A) physical health and B) well-being .
[2] The GHQ 12 is a version of the General Health Questionnaire which involves respondents rating themselves against a series of 12 statements, and screens for non psychotic-psychiatric disorders (such as poor mental health). The WHO-5 measures psychological well-being using five items covering positive mood (good spirits, relaxation), vitality (being active and waking up fresh and rested), and general interests (being interested in things) http: /www.who-5.org/

training they required, was a focus of debate between sites and raised issues about cost-effectiveness and managing (carers') expectations. Some implications of these aspects are considered in Chapter 3.

The sites often approached carer health in a holistic way, aiming to monitor and improve carers' mental and emotional well-being as well as their physical health. This was thought important because of the emotional strain carers can experience (Carers UK, 2004; Henderson, 2001). The well-being checks often included: taking stock of the caring situation; exploring whether carers had the opportunity to take a break from their caring role and what social support the carer had; exploring the carer's 'life-style', including opportunities for work, education, leisure and social activities; asking what support carers felt they needed; establishing if there were any environmental or safety concerns for the carer in their caring role; and providing financial advice (Table 2.3). The well-being checks were carried out by a variety of staff in the different sites (Table 2.4): in both the Redbridge and Camden sites 'well-being workers' carried out the well-being checks; while at the Tower Hamlets, Devon, and Northumberland sites they were carried out by nurses. As previously mentioned, the Trafford site adopted a slightly different approach, using case workers at the local carers' centre for their combined physical health and well-being checks.

In addition to providing both the physical health examinations and well-being health checks, most sites also offered some 'additional support activities'. These included running health days for carers (Devon, Tower Hamlets, Trafford), awareness raising / training for health professionals (Devon, Northumberland, Redbridge, Trafford) and training for carers (Trafford).

The extent to which health checks were 'carer-led' varied. Most sites provided a comprehensive health check, but attempted to prioritise those aspects of the health check which were of main concern to the carer, often using a 'well-being booklet' or questionnaire (completed by the carer) either prior to or during the check, to facilitate this. Four of the sites (Camden, Devon, Trafford, Redbridge) used a 'person-centred approach', developed in discussion with health and well-being workers, in which carers identified their needs and goals and the actions required to achieve their goals following their health checks. By contrast staff in the Northumberland site, who described the checks offered as 'health-led' (that is, the focus was on the health need(s) identified, either by the carer or by the person who undertook the check), developed a 'health checks' form completed by the clinical staff member conducting the check. Here follow-up plans involved referring carers to services identified as appropriate for them during their health check rather than focussing on carers' personal health and well-being goals, as in the other sites.

As well as providing initial health checks, most sites (all except the Camden site[21]) undertook follow-up reviews or re-checks. In the Redbridge site, follow-up reviews were provided at both 12 and 26 weeks; sites in Northumberland, Tower Hamlets and Trafford provided reviews at about 26 weeks and the Devon site offered annual reviews. Given the 18-month timescale of the DS programme, this variability in follow-up arrangements meant that for some carers, in some sites, no review took place during the delivery period[22], whereas other carers were reviewed (either once or more often) within the lifetime of the programme.

The extent to which sites focused on making the health checks accessible varied by site (Table 2.3). Many sites attempted to improve access by offering alternative care for the person being cared for, so that carers could attend the health checks being offered, as well as other medical appointments. Some sites, however, also (or instead) deployed specific strategies to improve and widen access, including: offering health checks in a choice of venues, including carers' own homes (Northumberland, Redbridge

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[21] In the Camden site, well-being workers helped carers to achieve their health and well-being goals, but in this site a follow-up check was not part of the delivery model.

[22] All sites made contingency plans for carers who had not 'completed' the processes during the delivery period, to ensure promised follow-up options would be available.

and Trafford); offering health checks at venues which certain groups of carers were more likely to attend, such as sports centres for young carers and local community centres (including the Hikmat Centre for ethnic minority carers in Devon); and offering more flexible appointment times, including in the evenings and at weekends (Redbridge and Tower Hamlets), with a view to making the checks accessible to a wider range of carers, such as carers in paid work[23].

The additional non-staff resources required by the sites varied according to the approaches adopted. Requirements for the health checks included: medical equipment (for the physical examinations), health checks documentation and guidance, questionnaires (for the well-being checks) and a venue from which to undertake the checks (Table 2.4). Often, staff training (in working with and understanding carers' needs) was also required for specific elements of the health check.

Innovation in health checks provision

The approaches adopted by the Health Checks sites included some innovations (Table 2.3), although the physical health examination represented an extension to an existing service in both the Devon and Redbridge sites. Both these sites had offered health checks to carers previously. The Devon site had carried out a similar, but small scale, pilot prior to receiving the DS funding. The Redbridge site had previously offered physical health checks to carers but, through the DS programme, was able to offer a more holistic approach combining the physical health checks with a well-being check. The Trafford site's approach was particularly innovative as it worked very closely with a carers' centre to deliver the health checks, which the site had not done before. A summary of the key innovative approaches adopted by the sites is provided in Box 2.2.

Box 2.2 Health Checks: key innovations adopted by sites

- Delivering health and well-being checks to carers using staff based in voluntary sector or carers' organisations, rather than health professionals (Camden[24] and Trafford).

- Delivering health checks in a choice of venues, including in carers' own homes (Devon, Northumberland, Redbridge, Trafford).

- New delivery arrangements and content, including checks to assess well-being in the physical health checks offered to carers (Camden, Northumberland and Redbridge).

Delivering health checks through partnerships

In five of the six health checks sites the lead organisation was either a local authority or a PCT, while in the sixth (Northumberland) it was led by an integrated health and social care trust (Appendix C, Table C.2). All sites worked with at least one local carers' centre, which often took a lead role in delivering the health checks. Some Health Checks sites also involved informal arrangements with large numbers of voluntary and other local organisations, which was quite different from either the Breaks or the NHS Support sites (see Chapter 3 for discussion of partnership working).

All Health Checks sites worked, in some capacity, with GP practices. In the Devon, Redbridge and Trafford sites, work with GPs and other staff in GP practices included new measures to identify carers, using 'Read Coding' to support this[25] (further aspects of working with GPs to support carers are

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[23] Flexible checks provision is mentioned in the local evaluation report for the Redbridge site, but does not indicate if these appointments were used or effective in enabling working carers to access a health check. The issue is not covered in the local evaluation report for the Tower Hamlets site.

[24] The approach used in the Camden site built on similar previous work with a local carers' organisation

[25] 'Read Coding' is a system used within the NHS which records on a patient/service user record certain patient / service user characteristics, including if the person is a carer: (http://www.connectingforhealth.nhs.uk/systemsandservices/data/uktc/readcodes)..

Table 2.4 Health Checks Sites: resources, partners and main carer beneficiaries

Approach to health checks provision	Staff resources needed	Other (non-staff) resources needed[1]	Partners' roles	Main carer beneficiaries	Evidence of demand for service / support
(A) Physical health examination	• Dedicated nurses (majority of sites) or other health professionals (health care assistants; pharmacists – Devon) to conduct physical health examinations. • Nurse adviser to support voluntary sector case workers conduct health checks (Trafford).	• Health check equipment (e.g. gloves, swabs, slides for blood check, etc). • Appropriate venue. • Budget for 'health day' events to promote services, provide advice and sometimes offer checks (Devon, Trafford). • Health check documentation. • Staff training to conduct carer health checks (e.g. protocol, vascular check, listening and problem solving skills). • Carer awareness training for management / clinical staff.	• PCT: employed nurses and other clinical staff who conducted physical health checks, overall management / oversaw projects in some sites. • Carers' centre: employed case workers who conducted checks (Trafford). • Local authority: overall management of projects or advisory role in some sites.	Carers with a demanding caring role / long term carers who neglect their own health, carers with untreated health conditions.	• Number of carers accessing services varied by site. Targets met (Devon, Tower Hamlets), lower numbers than expected in others (Camden, Northumberland). • Concerns about staff capacity to meet demand in many sites (Northumberland, Tower Hamlets, Trafford). • Waiting lists for checks (Camden).
(B) Well-being check	• Case workers to conduct (A) + (B) (Trafford). • Nurses / clinical staff to conduct (A) + (B) (Devon, Northumberland, Tower Hamlets). • 'Well-being workers' to carry out well-being checks (Camden, Redbridge).	• Questionnaires to measure well-being. • Health and well-being check documentation. • Appropriate venues. • Training for staff in well-being check protocol, and use of questionnaires (e.g. carer strain index, WHO-5).	• Carers' centres / carers' organisations: employed well-being workers and / or case workers. • PCT: employed nurses and other clinical staff (as above). • Voluntary sector organisations: received carer referrals for ongoing support. • Local authority (adult social services): received carer referrals for Carer's Assessments.	Carers with a demanding caring roles / high level of strain	• Number of carers accessing services varied by site. • High level of mental health need detected using GHQ-12 (Redbridge and Tower Hamlets), leading to increased referrals to specialist services (e.g. MIND, 'psychological therapies') and additional staff with mental health expertise (Tower Hamlets). • Waiting lists for referral to well-being support (Camden, Redbridge), or local authority carer support / assessments (Tower Hamlets).
(C) Accessibility of health checks	• Carers' organisations to provide respite care. • Staff able to provide health checks at flexible times / locations. • Voluntary sector staff to support ethnic minority carers to have health checks in suitable locations.	• Travel / subsistence for staff conducting checks in carers' own homes / flexible locations, particularly in rural areas (Northumberland). • Rental of premises and overheads for specialised locations (e.g. community centres for tailored checks for ethnic minority carers, sports centres for young carer health events).	• Voluntary sector carers' organisations: contracted to provide respite. • PCT or carers' centre: workers conducted checks at flexible times / locations (Redbridge, Tower Hamlets, Trafford). • Voluntary sector ethnic minority organisations: identified and supported ethnic minority carers (Devon). • Local authority and voluntary sector organisations: identified young carers through the Children's Trust partnership (Devon).	• Carers with an extensive caring role who find it difficult to leave the person they care for. • Carers reluctant to access checks through statutory organisations.	• Take up of alternative care lower than expected but higher where local carers' organisations were used (Trafford) or where paying friends / family for alternative care was an option (Tower Hamlets). • Positive carer feedback relating to offer of choice of location. High number of carers choosing to have check in own home (Redbridge). Higher numbers of ethnic minority carers taking up checks when offered in community centres (Devon).

Sources: case study interviews, local evaluation reports, quarterly calls, QRTs, site documents. Note: [1] Services also require marketing materials and publicity.

discussed in Chapter 3). Sites adopted different approaches to working with partner agencies and some of the roles of the partners are shown in Table 2.4. These arrangements varied according to the specific approach taken to service delivery in each site.

Adopting a flexible approach to health checks provision

Demand for both the physical and well-being health checks varied by site. Some sites encountered difficulties engaging with the number of carers they had initially predicted, while others faced the challenge of increasing staff capacity to meet demand (Table 2.4). In some cases (Camden and Redbridge) this led to waiting lists of carers (the extent to which sites engaged with carers and met their initial target numbers is outlined in Chapter 4).

At some points in the delivery period the number of carers coming forward for Health Checks was lower than expected, or it was felt that reaching out to particular target groups of carers was not working effectively. In response to this, some Health Checks sites added new approaches to engaging with providers and carers, or involved additional providers or organisations in delivery or engagement processes. The Tower Hamlets site, for example, adjusted its plans when delivery staff reported that the level of mental health need identified using the GHQ-12[26] was higher than anticipated, resulting in increased referrals to psychological therapies, collaboration with MIND (the voluntary sector mental health organisation), and the recruitment of a mental health worker. It also emerged in the Tower Hamlets site that many local authority staff were also carers, leading to additional provision of health checks for these individuals, as well as specific events tailored to their needs. The Devon site made changes in its mode of delivering health checks to young carers, responding to organisational and safeguarding issues which arose in delivering health checks in schools. The Trafford site modified how its health checks were delivered, introducing screening to establish if health checks were needed (to minimise numbers of carers receiving health checks when these were not really necessary). In the Northumberland site, the original broad scope of the health checks and the focus on environmental / lifestyle issues was reduced following feedback from staff and carers.

Challenges in health checks provision

Some ideas and plans proved especially difficult to implement in some (but not all) of the Health Checks sites. Difficulties included: partnership working to identify carers; following up referrals, and delivering health checks (including those with voluntary sector organisations, GPs, social services, pharmacists, learning disability and mental health teams); vascular checks; staff capacity to deliver time-intensive health checks; delivering health checks to young carers in schools (see above); follow-up checks / reviews; balancing health and well-being issues; managing carers' expectations of health checks; and delivering services in rural areas.

2.4   NHS Support sites

The seven NHS Support sites were expected to address some of the challenges within the NHS in delivering personalised and holistic services which treat carers as partners in care, and to demonstrate *'more integrated working between the NHS, social services and carers'* (HMG, 2008:16). The DH allocated resources to these sites to help them: to find effective ways of supporting carers through new work with GPs and their practice staff, hospitals and other NHS organisations; to develop new or more effective partnerships; and to raise awareness of carers among NHS staff and provide them with

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[26] The GHQ-12 is a version of the General Health Questionnaire which involves respondents rating themselves against a series of 12 statements, and screens for non psychotic-psychiatric disorders (such as poor mental health).

training and support where appropriate. The objectives of the NHS Support sites focused on:

- Improving carer health and well-being (five sites).

- Increasing recognition of carers as expert partners (four sites).

- Contributing to cultural change in the NHS (four sites).

- Improving support for carers (three sites).

NHS Support delivery: models and approaches

In the NHS Support sites, six main approaches were taken, as shown in Table 2.5: hospital based carer support; primary care based carer support; befriending and peer support; carer awareness training for NHS staff; improving information and documentation about and for carers; and delivery of and / or documentation for Carer's Assessments (for a more detailed summary of the activities offered in each site see Appendix B).

All seven NHS Support sites offered carer awareness training for staff and endeavoured to improve the provision of information and documentation about and for carers. The former included face-to-face training, and in some sites, on-line training and distance learning activities and typically involved providing health professionals with important information about carers, the services they could access in the local area and the importance of treating carers as expert partners (in the care and support requirements of the person they care for). This staff training was, in most cases, delivered by carer support workers or carer liaison workers. Staff in the Bolton site chose to deliver awareness training as part of mandatory induction training for new staff in the NHS Trust, which was the lead partner.

Information and documentation about and for carers was improved to ensure that carers had access to the information they needed, when they needed it, and that health care professionals had appropriate information about carer support and carer pathways, to enable better care co-ordination and a more responsive support system (see Table 2.5 and Chapter 3 for more details). At least five sites developed a carers' charter or carers' policy for their local organisations / trusts, offering guidelines for identifying and involving carers and respecting their views as key partners in providing care (Bolton, Halton and St Helens, Hastings and Rother, Swindon, West Kent). In the Swindon site the charter was used to develop a practical workbook on carer support. This was used to 'accredit health and social care services and teams' as staff were trained in carer awareness and support. This information was often disseminated by existing health care workers designated as 'carer champions', or by 'support' or 'liaison' workers employed as part of the DS activities. In one site (Northamptonshire) a specialist communications agency was contracted to produce a publicity, advertisement and information strategy (see Table 2.6).

Many sites (Hastings and Rother, Halton and St Helens, SW Essex, and West Kent) also developed support for carers which was offered in hospitals and in primary care settings such as GP practices (Table 2.5). The Swindon site also offered carer support, but in a hospital setting only, and the Northamptonshire site offered carer support but through GP practices only. This kind of service involved placing carer support / liaison workers in hospitals or GP practices or using existing staff as 'carer champions' who were responsible for identifying carers, providing them with necessary support, and signposting them to appropriate services elsewhere in the health and social care system. The South West Essex site identified carers in GP practices and hospitals and provided them with information, but chose not to deliver any direct services to carers. Instead it referred carers to further support provided elsewhere. Halton and St Helens also provided benefits advice by appointing an 'income maximisation officer' to work with carers in hospitals.

Table 2.5   NHS Support sites: main features and rationale of NHS support provision

Approach to NHS Support	Main features	Rationale	Innovation, enhancement or extension to service / support	Sites offering service / support
(A) Hospital based carer support	Hospital based carer support workers identified carers / worked with staff to identify carers. They provided support in hospitals including: listening to carers' concerns; providing advice and information; preparation for discharge; and signposting carers to ongoing support. Hospital based 'income maximisation officer' in Halton and St Helens.	Carers frequently report a lack of recognition and support in health care settings. Hospital based carer support aimed to increase early identification and support of carers in hospitals, particularly carers unknown to support services.	Extension (Hastings and Rother, South West Essex). Innovation (Halton and St Helens, Swindon, West Kent).	Halton and St Helens; Hastings and Rother; South West Essex; Swindon; West Kent
(B) Primary Care based carer support	Carer support workers / liaison workers in GP practices: identified carers in waiting rooms / clinics; worked with staff to identify carers; provided immediate support / assessment; and signposted carers to relevant services.	The number of carers registered in GP practices is often low when compared to the number of carers identified in local census data. Primary Care based services aimed to increase identification and support of carers in GP practices, particularly carers unknown to support services.	Extension (Halton and St Helens, South West Essex). Innovation (Hastings and Rother, Northamptonshire, West Kent).	Halton and St Helens; Hastings and Rother; Northamptonshire; South West Essex; West Kent.
(C) Befriending and peer support	Carer-led services in which carer volunteers provided support to other carers, including: peer support groups; befriending; carer cafés; holidays. Voluntary sector organisations generally facilitated these services.	Carers may describe a lack of social support, and poor recognition of their needs / expertise in delivery of healthcare services. Befriending / peer support services enabled carers to support other carers and build social networks, reducing isolation. This facilitated personalised support and carer involvement in service delivery as 'expert partners'.	Innovation (Bolton, Northamptonshire). Extension (Hastings and Rother). Not stated (Swindon).	Bolton; Hastings and Rother; Northamptonshire; Swindon.
(D) Carer awareness training for NHS staff	Training provided for NHS staff to improve their awareness of carers and their ability to identify carers. Included face to face training, and in some sites online training and distance learning.	Identification and referral of carers by healthcare workers is frequently low, reflecting a lack of knowledge of how to recognise and support carers. Training was designed to increase carer awareness among healthcare staff, thereby enabling them to identify and support carers who may not otherwise recognise themselves as carers or receive support.	Enhancement (Bolton). Extension (Halton and St Helens, South West Essex, Swindon). Innovation (Hastings and Rother, West Kent).	All NHS Support sites.
(E) Information about and for carers	Information points and notice boards in hospitals / GP practices / mental health services; documentation on pathways for referring carers; newsletters; websites for carers and professionals; updated carer registers; project workers / carer champions to provide staff and carers with information; carers' policies and charters.	People new to the caring role can find it difficult to access the right information at the right time. Healthcare professionals sometimes lack the necessary information to identify and refer carers to support. Sites aimed to improve the timely provision of information for carers, and establish clear pathways and information to enable professionals to refer and support carers more efficiently.	Extension.	All NHS Support sites.
(F) Carer's Assessments: delivery and / or documentation	New ways of providing Carer's Assessments included: shared assessments between health and social care; standardised assessment across different local authorities; auditing social care assessments; and assessments conducted by voluntary sector workers.	Assessment documentation often lacks consistency across organisations, and is sometimes described as not 'user friendly'. Sites aimed to increase numbers of Carer's Assessments, and to develop more consistent, comprehensive and user friendly assessment procedures.	Innovation (West Kent) Enhancement (South West Essex, Swindon). Extension (Bolton, Northamptonshire).	Bolton; Northamptonshire Swindon; South West Essex; West Kent

Sources: baseline statements, case study interviews, local evaluation reports, quarterly calls, QRTs, site documents.

Table 2.6 NHS Support sites: resources, partners and main carer beneficiaries

Approach to NHS Support	Staff resources needed	Other (non-staff) resources needed[1]	Partners' roles	Main carer beneficiaries	Any evidence of demand for service / support
(A) Hospital based carer support	Team of carer liaison / support workers. Line manager for this team. Carer champions identified from existing hospital staff. Income maximisation officer (Halton and St Helens).	New paperwork (e.g. for pathways / referral).	Carers' centre: employed and line managed liaison / support workers (majority of sites). PCT: overall management / supervision, employed liaison workers (Swindon). Acute / Hospitals Trust: base for hospital services.	Carers who had not previously received support / carers in a crisis situation following admission of person cared for to hospital / people new to caring role.	Generally high number of carers receiving hospital support. Some sites struggled to meet high level of demand (Halton and St Helens), and brought in additional staff (Hastings and Rother). Difficulties meeting high demand for benefits advice (Halton and St Helens).
(B) Primary Care based carer support	Carer support workers / GP link workers. Line manager for this team. Carer champions identified from existing GP practice staff.	Incentive payments to GPs for referring carers / participating in projects (Halton and St Helens, Hastings and Rother).	Carers' centre: employed and managed supported workers. PCT: overall management, supervision and co-ordination, engagement of GP practices.	Carers who had not previously received support / carers previously identified by their GP practice / people new to caring role.	Variable numbers of carers identified / supported in primary care; high in Halton and St Helens, low in Hastings and Rother. Waiting lists in Northamptonshire.
(C) Befriending and peer support	Co-ordinator to facilitate services / engage carer / organise training. Carer volunteers to deliver befriending and run carer cafés.	Training for carer volunteers. CRB checks for carer volunteers. Venue for support services and training.	Voluntary sector organisations: facilitated and supported the development of services; trained carer volunteers. PCT: overall management.	Isolated carers / carers who wish to support other carers or be involved in service development and improve their skills.	Variable numbers of carers receiving services: low in Bolton, high level of engagement described in Northamptonshire; high number of carers referred to befriending in Hastings and Rother.
(D) Carer awareness training for NHS staff	Staff delivering training - carer support / liaison workers (majority of sites), workers employed by the PCT, or professional trainers. Indirect costs of staff taking time out to receive training.	Training resources (e.g. DVDs, information packs, online resources). Expenses for carer volunteers delivering training.	Carers' centre: employed and managed support workers who delivered training (Halton & St Helens, Hastings & Rother, Northamptonshire, South West Essex). PCT: staff delivered training (Swindon, Bolton), engagement of NHS staff.	Carers in GP practices / hospitals benefitting from improved awareness / support from staff.	Target number of staff taking up training exceeded in some sites (Halton and St Helens). Local evaluation staff surveys demonstrated a prior lack of knowledge of carers, and a positive response to training by staff (Bolton, Halton and St Helens).
(E) Information about and for carers	Carer champions or support / liaison workers to provide carers and staff with information in GP practices and hospitals. Staff to develop marketing and information. Administrative support.	Information materials. Events and roadshows.	Specialist communications agency (Northamptonshire). All partners (including carers) involved through steering groups.	Carers attending GP practices / hospitals with person cared for who have not received support previously, or were not fully aware of what is available.	In a baseline survey, GPs frequently identified the need for more information on support and services for carers, and most described the DS project as improving availability of this information (South West Essex).
(F) Carer's Assessment: delivery and documentation	Carer support workers to conduct assessments on behalf of local authority (Northamptonshire, West Kent). Referral to local authority for Carer's Assessment (Bolton, South West Essex). Staff to gather carer feedback on Carer's Assessments (Swindon). Managers to develop Carer's Assessment documents.	New Carer's Assessment documents. Information for staff on conducting assessments.	Carers' centre: staff conducted Carer's Assessments. Local authority: developed new Carer's Assessment procedures.	Carers who require a Carer's Assessment.	Increased numbers of Carer's Assessments (Bolton). Waiting lists for assessments (South West Essex). Carer feedback confirmed need for improved procedures (Swindon).

Sources: case study interviews, local evaluation reports, quarterly calls, QRTs, site documents. Note: [1] Services also require marketing materials and publicity.

Some sites (Bolton, Northamptonshire, Swindon) offered befriending and peer support services. These were usually facilitated by voluntary sector organisations and aimed to involve carers in service delivery as 'expert partners' and to assist carers in providing mutual support (Table 2.5). The Hastings and Rother site did not provide these kinds of services directly, but signposted and referred carers to befriending services offered elsewhere. These peer support services included coffee mornings or 'carers' cafés' where carers and volunteers could socialise and offer support and guidance to each other (Bolton, Northamptonshire, Swindon) and peer support groups, holidays and other activities run by carers, for carers (Northamptonshire).

Four sites (Bolton, Northamptonshire, South West Essex and West Kent) developed new ways of providing Carer's Assessments. These included: shared assessments between health and social care (West Kent); a standardised assessment form across local councils (South West Essex); auditing health and social care assessments using carer feedback (Swindon); and voluntary sector workers conducting assessments on the local authority's behalf (West Kent).

As well as providing the support outlined in Table 2.5, most sites also offered some 'additional support activities', including: providing and delivering carer health checks (Bolton, Hastings and Rother) and promoting carer health checks (West Kent); carer training (Bolton, Swindon, West Kent) which sometimes (but not always) built on or adapted the 'Caring with Confidence' training programme; and support directed at specific groups of carers, for example young carers (Bolton and Northamptonshire) and ethnic minority carers (Swindon). Several sites also provided targeted use of direct payments (Bolton) or personal health budgets for carers (Northamptonshire[27]).

In the NHS Support sites, activities were delivered by a wide range of staff, as appropriate to the specific services offered (see Table 2.6). Thus, for example, health checks were carried out by senior nurses (Bolton), carer liaison / support / recognition workers worked in GP practices and hospitals to increase the number of referrals to the DS service and to support carers (Northamptonshire, Halton and St Helens, Swindon, South West Essex).

The additional non-staff resources required by the sites varied according to the approaches adopted. Resources needed for the NHS support services included: the development of new documents (including Carer's Assessments) and information sources; new marketing materials for GP practices, hospitals and road show events; new systems for carer referral / pathways; venues for training; and incentive payments for GPs, either to refer carers or to encourage them to participate in the programme (Table 2.6).

Innovations in NHS Support

Almost all the NHS Support sites offered innovative services to carers (or a way of offering and developing carers' services). Providing hospital based carer support was particularly innovative in the Halton and St Helens and Swindon sites, whilst the provision of carer support in primary care settings such as GP practices was innovative in the Hastings and Rother and Northamptonshire sites. The Bolton, Hastings and Rother, Northamptonshire and Swindon sites all attempted new approaches to befriending and peer support, and both the Hastings and West Kent sites offered carer awareness training for NHS staff for the first time. A summary of the key innovative approaches adopted by the sites is provided in Box 2.3.

Delivering NHS Support through partnerships

In all seven NHS Support sites the lead partner was an NHS organisation (see Appendix C Table C.3). All sites also had partners in at least one local authority, although in some instances local authorities were only involved in the steering group and had no role in delivery (see Chapter 3 for further discussion of

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[27] Northamptonshire was a DH pilot site for personal health budgets.

> ### Box 2.3 NHS Support: key innovations adopted by sites
>
> - Providing direct carer support in an NHS Acute Trust (Halton and St Helens).
>
> - Providing staff to work directly with carers in GP practices (Hastings and Rother and Northamptonshire).
>
> - Providing benefits advice through an income maximisation officer based in hospitals (Halton and St Helens).
>
> - Offering befriending, peer support and carers' cafés (Bolton, Northamptonshire, Swindon).
>
> - Introducing assessment and support workers to carry out Carer's Assessments on behalf of the local authority (West Kent)

partnerships). All NHS Support partnerships also involved other NHS organisations (hospital trusts, mental health trusts, GP practices) and most worked with a local carers' centre. The different approaches sites adopted in working with partner agencies, and some of the roles of the partners, are shown in Table 2.6. These varied according to the approach taken in the sites.

Adopting a flexible approach to NHS support

Demand for the support offered varied by site and the particular approach taken (Table 2.6). Sites offering hospital based carer support reached large numbers of carers and some sites had difficulty meeting the high level of demand for this service. The Hastings and Rother site responded to this demand by recruiting additional staff. The hospital based benefits advice service offered in the Halton and St Helens site had particularly high demand from carers. Similarly, demand was relatively high for the carer awareness training and in the Halton and St Helens site the staff take-up of the training exceeded the initial target. The take-up of Carer's Assessments increased in the Bolton site and there were waiting lists for Carer's Assessments in the South West Essex site. However, demand for Primary Care based carer support and the befriending and peer support services was more variable.

Staff in the NHS Support sites reported responding creatively to various challenges and difficulties. These included points when the number of carers receiving services or the engagement of particular target groups of carers was lower than expected. In response to this, three NHS Support sites added new approaches to engaging with providers and carers, or involved additional providers or organisations in delivery or engagement processes. Some sites identified new opportunities to develop their work and added plans not included in the original bids; for example, the Hastings and Rother site decided to add health checks to its provision, and the Swindon site added a liaison worker to work with carers from ethnic minorities to address an identified need.

Challenges in NHS support

Some ideas and plans proved especially difficult to implement in some (but not all) of the NHS Support sites and included: engagement with GP practices; a befriending service (Bolton); and managing the workload of carer support workers when demand for services outstripped capacity to deliver it. An additional challenge experienced by carer support workers was the difficulty of accessing IT systems in NHS settings (Northamptonshire), or lacking a base from which to work in GP practices and / or hospitals (Halton and St Helens and Northamptonshire). Carer awareness training was not always easy to organise with busy NHS staff in hospitals and GP practices, although some sites overcame this difficulty by offering more flexibility in the delivery of training.

2.5   Local evaluation of the Demonstrator Sites services

The Department of Health expected, and recommended, that all sites would undertake a local evaluation (although the form this should take was not specified) and all sites, in their initial bids, committed to writing a local evaluation report. All sites spent at least some funds on local evaluation and some, by agreement with the DH, carried part of their funding allocation over from the final quarter of planned delivery to June 2011 so that local evaluation studies could be completed. Some sites made their reports available by publishing them on-line, and all were asked to submit their reports to the national evaluation team[28].

The local evaluation reports vary considerably in the range and detail of the data collected and in the methods used (see Appendix C, Table C4). Some mainly rely on management information or carer feedback forms, while others use a wide range of qualitative and quantitative evaluation approaches. All refer to monitoring data (e.g. on the number of carers to whom services were delivered), collected locally. Although many sites originally aimed to gather evidence to assess cost-effectiveness, this proved challenging in all types of site (see Chapter 1). Some sites employed external research agencies or universities to conduct some or all of the local evaluation work.

In many sites the local evaluation included a survey of carers, often conducted in two waves. In three Breaks sites (Bath and NE Somerset, Torbay and Liverpool) the local evaluation attempted to measure changes in carers' health and well-being using the General Health Questionnaire (GHQ-12). The local evaluation for the Bristol site examined changes in well-being using the 'Birmingham Quality of Life tool', while the studies in the Derby, Liverpool and Torbay sites involved analysis of self-assessment forms. The local evaluation for the East Sussex site used observation of care groups and the study for the Lewisham site used comparator groups to evaluate the relative benefits of services. The local evaluations for both the East Sussex and the Liverpool sites included documentary review and analysis.

All the local evaluation studies completed in the Health Checks sites sought to measure impact / improvement in health and well-being using different measures, including; carer strain indices (Devon, Northumberland), General Health Questionnaire scores (GHQ-12) (Devon, Redbridge, Tower Hamlets) and the WHO-5 well-being index (Camden). Many of the local evaluations measured and compared carer scores before and after a check, and in two local evaluation studies comparator groups (carers who had not received health and well-being checks or who had received a different model of check) were incorporated as part of a 'quasi-experimental design' (Camden, Trafford). In addition, the local evaluation for Redbridge explored how different predictor variables related to GHQ-12 scores. The local evaluations in the Northumberland and Trafford sites collected information in focus groups with carers which were conducted by peer interviewer carers.

The local evaluation studies conducted in most of the NHS sites also explored ways of measuring or assessing improvements in health and well-being, again using the GHQ-12 (Bolton) and the Carer Strain Index (Swindon) but also employing the Edinburgh-Warwick Well-being Scale (in the South West Essex site) and in one case a 'well-being wheel' (Hastings and Rother).

Staff surveys used in the local evaluations often involved a baseline and follow-up to assess changes in awareness, attitudes and practices. In some sites the local evaluation study involved asking staff to complete feedback forms following training to explore its impact on carer awareness (Hastings and Rother, Swindon, West Kent), and in the local evaluations in the Hastings and Rother and Northamptonshire sites, support workers completed self-reflection diaries.

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[28] Sites were asked to make their local evaluation reports available to the national evaluation team in June 2011, although not all were able to do this.

While in many sites the local evaluation explored options for examining cost-effectiveness (using the 'tribal tool' and other approaches), ultimately this proved too challenging in some. The cost and benefits analyses reported in the local evaluation reports are discussed in Chapter 6.

Key Findings

This chapter has mapped the range of services delivered in the different types of Demonstrator Sites, delivering breaks, health checks and enhanced support for carers in NHS settings, through new partnerships, with new delivery models and in new ways.

- Overall, the 25 Demonstrator sites explored a wide range of ways of providing services and of engaging and supporting carers. Most sites did this in ways consistent with the aims the DH had for the DS programme, offering carers personalised services in new ways.

- Three main approaches to breaks provision were offered by the sites: specialised short-term respite for carers of people with dementia / mental ill-health; alternative care in the home; and personalised breaks (which were based on carers' demand / needs and took a variety of different forms (ranging from funding for holiday breaks to equipment and domestic goods).

- Sites providing health checks offered either combined or separate physical health examinations and health and well-being checks; some experimented with delivering these using staff who were not clinically qualified.

- NHS support services included supporting carers in hospital and primary care settings, befriending and peer support activities, awareness training for staff, and improving information, documentation and Carer's Assessments.

- All three types of site focussed on the accessibility of support services to carers. Breaks sites explored innovative approaches such as on-line booking systems and mechanisms for accessing a break without completing Carer's Assessments. Health Checks sites offered the checks in a variety of venues including in carers' own homes and in local community centres, and the NHS Support sites offered new ways of providing Carer's Assessments through, for example, subcontracting to voluntary sector workers.

- Most sites developed at least some new services which were innovative, and many made significant changes to existing provision which they considered made a positive difference to carers.

- Almost all sites worked with partners across the health, social care and voluntary sectors, and some also engaged with other agencies, including some social enterprises and some private sector organisations. The role of the partner agencies varied by site type and the specific activities offered.

- Demand for services varied by site and by the approaches offered. Some sites and some services had a high level of demand which sometimes had implications for staff capacity and resulted in waiting lists for services. For other sites and services, demand was lower than initially expected. Many sites took a flexible approach to delivery and adjusted the type and level of services offered accordingly.

Chapter 3
Integrating Health and Social Care: partnerships which support carers

Gary Fry with Benedict Singleton and Sue Yeandle

3.1   Introduction

The Demonstrator Sites programme was developed to achieve goals relevant to carer health and well-being identified in the 2008 National Carers' Strategy (HMG, 2008). The vision for the future support of carers set out in the strategy implied significant change in the health and social care system and, as noted in Chapter 1, the DS programme aimed to enhance the evidence base on how the changes involved could be achieved, exploring their wider implications for the people and organisations involved. This chapter focuses on the impact on staff and organisations of the DS activities and delivery processes described in Chapter 2. It considers how the programme: affected the workloads and working relationships of the professionals and practitioners involved; the nature and effectiveness of the partnerships developed to deliver the new / enhanced activities; the extent to which the new arrangements led to improved system responsiveness and care co-ordination; and the impact of the DS on existing carer services. Evidence in the chapter has been drawn from all aspects of the evaluation study, including documents, interviews, survey data and case study material, and from across all three types of DS.

3.2   Professionals and practitioners: impacts on roles

The DS programme had a number of implications for the way staff working in the DS to deliver enhanced support to carers operated. Across and within sites, roles and duties varied considerably. This was hardly surprising (and was as envisaged when the DS programme was commissioned), as there was no single model of service delivery (even for sites of the same type) and sites had different budgets, different local challenges to address, different histories of providing carer support, and involved differently configured partnerships. Data collected showed that in implementing their plans the 12 Breaks sites often had service co-ordinators, trained care workers and some volunteer staff; the six Health Checks sites all recruited and worked with nursing and clinical staff and specially trained voluntary sector workers; and the seven NHS Support sites employed carer support workers, carers' champions, and some benefit advisors, who collaborated closely with existing hospital and primary care staff. The roles of different partners and the staff within them in the three different types of DS are indicated in Chapter 2 in Tables 2.2, 2.4 and 2.6.

Most of these staff had a background in the health and social care professions and had previously been involved in providing services to carers. Many had social care training or an interest in supporting carers and some had personal experience of being a carer. They included staff who were able to apply existing skills to their DS roles based on considerable professional experience of providing carer support. This facilitated engagement with partner organisations but also contributed new perspectives on approaches to working with carers.

In some sites, the lead organisation assigned job roles in the DS to existing staff, rather than recruit new workers. Sometimes this was done to ensure that carers would not have to deal with too many different people when accessing DS services. In some sites, where this approach was not taken, staff felt in retrospect that employing dedicated staff focused exclusively on DS delivery would have been a more effective way of operating.

Staff frequently mentioned an increase in their workloads, an issue which was indicated in the Key Actor Survey by more than half the sites that responded. The increase was difficult to quantify, as some worked full-time and only on DS activities, while others continued to have additional duties or worked part-time. In sites with previous experience of delivering services to carers (see Tables 2.1, 2.3 and 2.5), most staff reported that their increased workloads were manageable, that their organisation had been well prepared for the changes involved and that most of the additional work associated with setting up the DS had 'levelled out' when activities were 'up and running'. The additional work mentioned included administration, activity / financial monitoring, project management, external presentations and attending partnership meetings. In those sites where carer referrals increased significantly, rising numbers of carers supported had also added to workload pressures on some staff.

The new ways of working resulted in more effective teamwork in some sites, with staff reporting that all colleagues made a contribution to project development. Thus in one of the Health Checks sites (Trafford) staff reported that consultation within the team improved after moving to new premises, bringing the DS team together. This enabled staff conducting health checks who were not clinically qualified to benefit from the support of a qualified nurse, helping to overcome early difficulties in service delivery and increasing the number of health checks delivered. Better understanding among team members of each other's job roles was also recorded in many of the DS documents reviewed, and one member of staff explained that, when workloads increased unmanageably in the team, improved knowledge of these colleagues' responsibilities enabled staff to help each other and resolve problems.

In most sites (all types), staff reported increased awareness of carers and their needs and circumstances. This was mentioned in many staff interviews and by the programme's Expert Advisers. Views about the impact of greater carer awareness were mixed, however. Some senior staff claimed that, while their colleagues had become much more conscious of carers and their needs, this had not fundamentally altered the way their organisation operated. A practice manager working in primary care in a Breaks site, focused on delivering improved access for carers, observed:

> As a practice we're looking at carers and we're looking at people who are suffering from dementia and so, if someone is highlighted, we'll be looking now to see, 'Do they have a carer? What's the impact there?' So it's probably just increased awareness really for us as a practice; it hasn't really altered the way we do what we do.

In other sites, greater awareness of carers among staff had a considerable impact on the organisations involved, marking a significant shift in focus in the way they worked with carers. As a DS project manager based at a hospital in one of the NHS Support sites delivering a wide range of support reported:

> The main benefits for the PCT will be that we 'think carer' and we 'think carer' with any programme that we're developing. So we don't think just 'patient'; we think 'patient-carer'. And as a result of that, we can demonstrate, by supporting carers, it will have a positive impact on the way that health services are used, that the health of carers is better, which then has a knock-on effect to the use of services.

Greater awareness of carer issues tended to spread to other organisations in the partnerships once knowledge of carers was established among staff in the lead organisation responsible for planning and delivering the site's activities. In the case study sites, staff often noted that the DS activities had increased carer awareness among colleagues who had previously seemed unwilling to focus on carers and their needs, often mentioning GPs, nurses, and other health professionals. They pointed out that this change had helped considerably with engaging carers, as staff working in health settings could often identify carers not previously in touch with support services.

Even in organisations with a previous history of delivering support to carers, staff had needed to adjust to the expectation that they would engage with and provide services for groups of carers they had not

targeted in the past, such as young carers, carers from ethnic minority communities, and carers of people with specific needs or conditions (learning difficulties, dementia, or substance misuse problems, for example). They had needed to adapt existing working methods to engage effectively with these groups, accessing schools to target young carers, negotiating language barriers with carers in some ethnic minority communities (sometimes enlisting the support of local community groups) and addressing complex feelings and emotions in working with carers of people with substance misuse problems. The innovative strategies staff employed to engage with new or different client groups were, on the whole, fairly successful, with particular success achieved across all three types of site with ethnic minority carers (e.g. culturally sensitive support and advice), carers of people with dementia / mental ill health (e.g. breaks services with appropriately trained staff), young adult carers (e.g. support and advice on employment), and older people (e.g. health and well-being checks) (see Chapter 4, Tables 4.2, 4.3, 4.4). This work involved developing knowledge of additional, specialist services relevant to the target groups in question and accessing previously unfamiliar networks through which staff could engage with new carers and signpost them to appropriate support. Sites' performance in reaching their target groups of carers is discussed in Chapter 4.

Many staff mentioned that their DS work involved developing: better time management and work prioritisation strategies; a more focussed approach to roles: and different and more effective ways of working. This was reported by more than half of the Key Actor Survey staff respondents (in all types of site). Some new tasks proved challenging: monitoring carers' participation often involved adapting existing databases, and some staff needed training in the skills required. The programme involved quite detailed progress reporting and monitoring which many staff said was time-consuming and, in their experience, unprecedented in the detailed information required. Staff in some sites needed to develop new assessment tools (such as surveys, focus group topic guides) to capture carers' experiences of the services offered. Many accepted that participating in a demonstrator programme required such monitoring, and some felt the new systems and evaluative skills acquired would be useful in the future, or that carers would benefit from a more robust approach to service delivery. However, compliance with some reporting requirements (of both the DH and the national evaluation team) was extremely variable (as discussed in Chapter 1 and Appendix A in relation to the monitoring data supplied), and staff in some sites clearly struggled with, or were reluctant to implement, the tasks involved.

Changes in how staff conducted Carer's Assessments were reported in some sites. Despite the legal requirements of Carer's Assessments including a focus on carers' health and well-being, and balancing caring with other aspects of their lives (such as work and family), many DS staff said that in the past these had focused primarily on the carer's capacity to cope with supporting the person(s) they cared for. The DS programme had allowed staff to focus more explicitly on the needs of the carer, with the carer's personal need for support more central to assessment outcomes. Some staff said conducting assessments in this way was challenging, involving considerable changes in the procedures involved, although many felt it had improved the assessment process, giving them the capacity to support carers with more flexible care packages and holistic support. In one Breaks site delivering specialised short-term respite for carers of people with dementia / mental ill health (East Sussex), voluntary organisation staff assisted social workers in conducting Carer's Assessments, which, voluntary organisation staff reported, was a more economic method and also freed up social workers' time to carry out other tasks. Carers also benefited from this approach by having people they perceived (voluntary organisation staff) to be dedicated to their needs.

While the changes above applied in all types of DS, some were specific to staff in particular roles or parts of the health and social care sector. In the Health Checks sites, staff with extensive experience in GP practices, hospitals and other healthcare settings found they needed to adapt their working methods, enquiring about carers' well-being (rather than focusing only, or primarily, on assessing health needs) and, in some sites, conducting health and well-being checks in carers' own homes. Interviews with staff

in the Health Checks sites revealed that to provide a comprehensive support service, staff needed to allocate more time to their direct contact with carers, especially in sites delivering well-being checks, as the content of these was shaped by carers themselves and took time to explore. This approach led to some rearrangement of work plans, especially where health checks were offered to carers at home – fewer visits were carried out, so that more depth in the assessment could be achieved. Others noted that it had taken time to get used to discussing private issues with carers, and that staff had found this especially difficult if the carer was seen in the presence of the person they cared for (though advice from more experienced colleagues often helped overcome this problem). Delivering health checks was initially challenging for carer support staff who did not hold clinical qualifications, but with experience and training these colleagues had been able to provide a holistic review of carers' needs in a way which most carers appreciated (see Chapter 5 for carers' responses to the DS support).

Some staff indicated that when the DS work began, there was a degree of reluctance to embrace new working methods, especially in sites where clinically trained staff whose roles were normally centred on patient health were required to adopt a more holistic and carer-focused approach. As the DS work progressed, however, these staff often became positive about the different working methods. An interviewee in a NHS Support site delivering hospital based carer support explained:

> *It was difficult because this is a big organisation and some of the things that are in place have got quite a history to them and people have invested a lot of time and effort in them, so people feel quite protective of the way they do things. However, it has actually come out to be a positive thing, because you end up challenging some of the stuff that's been developed over time.*

Interviewees in other sites reported similar changes in working arrangements. In sites where most staff were health workers, or where providing a service to carers was new (mainly Health Checks and NHS Support sites) some staff felt their new job roles did not fit well with their professional training and reported a lack of existing knowledge about carers' needs, referral networks and available support services. Some embraced the new ways of working as opportunities for professional development or a change of focus in their career, but others needed specific training before they could adjust to the new arrangements, particularly in the NHS Support sites (Box 3.1).

Box 3.1 Carer awareness training for staff

The NHS Support site in Bolton (led by a mental health NHS Foundation Trust) conducted staff surveys prior to delivering the DS activity. Results showed that many clinical staff (e.g. nurses in hospitals) lacked knowledge of how to support carers. Responding to this, the Bolton site developed a training course which it delivered as part of the Trust's mandatory induction for all new staff. This focused on respecting carers as expert partners, issues relating to Carer's Assessments, and providing support to meet carers' service needs. This training was effective in providing staff with a greater knowledge and awareness of carers, and skills and knowledge about their support needs, which could be incorporated into their everyday working practices. Surveys conducted after the training showed that 84% of staff said that the course had been appropriate to their role, and 88% said that it had 'broadened/refreshed their knowledge of the caring role.' This training course was supplemented by an e-learning package which could be accessed at any time by staff working in the organisation.

Source: Bolton Local Evaluation report.

In implementing their plans and activities, some staff experimented with temporarily relocating to the premises of partner organisations. Some carers' centre staff established a 'presence' in local GP practices or in hospitals so they could make contact with carers accompanying those they cared for to medical appointments. This involved 'networking' with staff in the host organisation (sometimes training them in carer awareness) and ensuring promotional literature (e.g. newsletters, posters) was routinely available there to carers. Some sites found this a successful way of targeting carers; for others, it was problematic. In one rural Health Checks site (Northumberland), a carers' centre worker developed direct relationships with GPs, resulting in many carers being referred to her. In one NHS Support site (Hastings and Rother), having a carer support worker located in a GP practice did not produce any significant increase in carer referrals. Staff described these new arrangements as both challenging and rewarding. Many felt they enabled them to engage with and influence other professionals and practitioners in new ways which were helpful in raising their awareness of carers. When difficulties arose, some staff pointed to the relative willingness to engage with the programme (or otherwise) of individual GPs as the main reason for success or failure (see section 3.3).

Working within the framework of the DS programme involved a real shift in emphasis in the way carer support was provided for many staff. These staff felt they had been able to adopt a genuinely innovative approach, supporting carers to make decisions about their own support and replacing previous arrangements in which, as professionals or practitioners, they could only present carers with rather limited options and choices. Adopting a truly personalised approach to carers had nevertheless been challenging, they said. This was partly because carers sometimes needed to be persuaded that such an approach was possible in the social care system (many were sceptical), but also because it could be difficult to convince other professionals and practitioners that this flexibility would benefit both carers and the health and social care system. Some had met with resistance in the early stages of their work, especially in Breaks sites where more conventional concepts of what 'breaks' for carers involve were sometimes strongly embedded in other colleagues' approaches and organisational arrangements. Staff in one Breaks site offering support to carers through equipment and domestic goods funding (Sunderland) reported that some colleagues had initially resisted the idea that this way of offering carers 'a break' (e.g. a mobile phone) could legitimately be categorised as a breaks service.

Despite the changes in staff roles and responsibilities, there was very limited evidence from the health and social care professionals involved (GPs and their practice staff, social workers and other local authority staff) that the new work was particularly onerous or disruptive to existing roles. Once staff became used to what was required (such as using new referral networks) the new tasks and arrangements seemed to be accommodated quickly. In one of the Breaks sites delivering well-being support services (Bristol), for example, a social worker conducting Carer's Assessments and referring carers to the local DS team reported that the additional work was manageable, and that this part of her workload accounted for less than 20% of her role. A hospital consultant at a Breaks site delivering specialised short-term respite for carers of people with dementia / mental ill health (East Sussex) described the DS work he carried out (referring carers of patients to DS services) as a small but very useful part of his role. A GP, a surgery receptionist and a local authority housing officer made similar comments. These staff expressed enthusiasm for the DS activities and considered them a valuable addition to the services they offered.

In the voluntary sector organisations, however, staff seemed to experience a larger increase in workload, perhaps because they tended to be responsible for additional outreach work with carers rather than for identifying them in routine contact with patients and clients, as usually happened with health and social care staff. Most readily accepted this widening of their responsibilities, feeling the new activities fitted well with their own organisational plans and seeing the programme as a valuable opportunity to develop their organisation's work. Some said the DS work provided a valuable 'capacity building' opportunity and welcomed the chance to work with local authorities and PCTs. They felt they had benefited from the

knowledge of staff with greater experience of bidding processes, financial management and developing large projects. In smaller organisations most staff felt they had been treated with respect (rather than, as one interviewee at a Health Checks site put it, 'the junior partner'). They felt their expertise had been valued, and that engagement in the site activities had allowed them to grow as an organisation, becoming more 'visible' in the locality, with a greater capacity to engage with a wider range of carers.

3.3   The role of partnerships

As outlined in the DH prospectus, all Demonstrator Sites were expected to:

> *commit to working closely with colleagues in the health and social care system as well as, where appropriate, housing and the third or private sector in order to achieve care that is more responsive and better outcomes for carers and those they support.*
> *(DH, 2009)*

In procuring the programme, the DH had emphasised that delivery partnerships should include NHS organisations (including GP practices), local authorities and voluntary sector organisations, and that those bidding should also engage with other organisations where appropriate. This is in line with recent government recommendations for PCTs to work with local authorities and carers' organisations to develop policies, plans and budgets to support carers. The Princess Royal Trust for Carers and Crossroads recently found that despite evidence of some successful inter-agency co-operation, some barriers existed. However, their report claims that these can be overcome by 'close personal relationships and the support of senior staff' and that these 'appear to be the key for successful co-operation' (PRTC, 2011: 13).

Evidence in the national evaluation study shows that the DS programme assisted relevant organisations in developing stronger relationships. In their contacts with the evaluation team, almost all staff in the DS indicated a desire to create better partnerships across different sectors and an expectation that these would lead to better care co-ordination and improved system responsiveness. DS staff frequently reported that they were trying to embed the changes they were delivering within their own organisations (so these could outlive the DS programme) and said they believed the changes involved would enable their organisations to work more efficiently and effectively in delivering support to carers in the future.

Overview of partnerships

Most sites worked only with the organisations mentioned in the partnership plans in their bids for DS funding and did not later adapt this aspect of their plans. A few drew extra partners in as their work progressed, engaging additional voluntary organisations in programme delivery or enlisting other organisations (mostly universities) to conduct an independent local evaluation of the DS activity. One of the NHS Support sites found the partnership plan in its original bid was too ambitious and reduced the number of partners involved; and one of the Health Checks sites added more partners than originally planned as a way of tackling unexpected difficulties in engaging carers.

In the Breaks sites, partnerships were mostly led by local authorities (10/12 sites), although in Bath and NE Somerset leadership was shared between the local authority and the NHS trust and the Torbay site was led by an integrated care trust (Appendix C, Table C1). Lead organisations normally supplied project management and governance as their main contributions to the partnership, although in at least five sites they also played a role in delivering breaks or other services (Bath and NE Somerset, Bristol, Derby, Lewisham, Warwickshire). In some sites the lead organisation used DS resources to recruit and employ project staff on a fixed-term basis (Bath and NE Somerset, East Sussex, Sunderland, Warwickshire), while in other sites, some voluntary sector organisations were paid to deliver breaks services or assessments on an *ad hoc* basis (e.g. Bristol).

All but two of the Breaks sites included voluntary sector organisations in their partnerships (Appendix C, Table C1). Voluntary sector partners often played a role in delivering the breaks (or other aspects of the services offered to carers), in some cases providing staff to deliver these services (funded via the DS budget in varying ways) and providing specialist skills (Bath and NE Somerset, Bristol, Derby, East Sussex, Hertfordshire, Nottinghamshire, Suffolk, Torbay, Warwickshire). Five sites worked in partnership with carers' centres or carers' organisations (Derby, East Sussex, Nottinghamshire, Sunderland, Torbay), and in almost all other sites relationships were formed with carers' organisations based in the local area to support or deliver the project (without formally drawing them into the partnership – see below). Three sites involved voluntary sector or carers' organisations very actively in identifying and engaging carers (Bristol, Suffolk, Torbay), usually asking them to recruit carers in specific target groups[29] or to disseminate information (Derby and Nottinghamshire) (see Chapter 4). Some sites involved voluntary sector partners in project governance or as advisers, again often including carers' organisations (e.g. Derby, Lewisham, Liverpool, Suffolk).

Some Breaks sites involved other organisations in delivery, with many working particularly closely with NHS organisations. These were involved variously in: project management and governance (Derby, Hertfordshire, Lewisham, Liverpool, Suffolk, Warwickshire); making programme referrals (East Sussex, Lewisham, Sunderland); and delivering or leading on aspects of the programme (Nottinghamshire, Suffolk, Sunderland, Warwickshire). NHS organisations sometimes played a role in distributing programme information (e.g. Warwickshire). Two sites (Bristol, Derby) worked with NHS organisations to access GPs to participate in their Breaks programme.

Leadership arrangements in the partnerships formed to deliver the Health Checks varied (Appendix C, Table C2). In three sites, the lead organisation was an NHS organisation (Devon, Redbridge, Trafford), in two a local authority (Camden, Tower Hamlets) and in one an integrated care trust (Northumberland). Lead organisations typically provided a project management or governance role for the DS. Most of the Health Checks partnerships encompassed NHS organisations and local authorities[30]. NHS partner organisations were variously involved in: delivering health checks (Camden, Devon); having an advisory role as part of project steering or management groups (Devon, Tower Hamlets); providing links to other partners or to care pathways (Northumberland); and providing access to GPs (Tower Hamlets). The roles played by local authorities in the health checks partnerships included project planning, management and governance (Devon, Redbridge, Trafford) and aspects of health checks delivery (Devon, Redbridge).

All Health Checks sites' partnerships included voluntary sector organisations, often carers' organisations or organisations supporting people with specific health conditions. As already discussed, in some sites, project workers were based in the premises of these partners (Camden, Northumberland, Tower Hamlets). Voluntary sector organisations, including carers' organisations, were involved in delivering the health or well-being checks in some sites (Camden, Redbridge, Trafford) and in managing or providing additional services (Camden, Trafford). In two sites they were important in engaging carers and focused their activities on specific target groups (Devon, Tower Hamlets). Voluntary organisations also provided more general support for the Health Checks sites. In the Devon site, a carers' organisation contributed to the development of the project and provided a venue where health checks were carried out (by staff of other organisations). In other sites they received referrals from or made referrals to the DS (Northumberland, Tower Hamlets) or contributed awareness-raising, promotional or marketing activities (Northumberland, Redbridge, Trafford). Some Health Checks sites involved voluntary sector organisations in project governance, for instance through steering or management groups.

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[29] In the one site where this did not happen (Bath and NE Somerset) there were difficulties in engaging with the target number of carers to be supported, with only 36% of the original target achieved, although this was not the only site where reaching target numbers of carers was difficult. The four Breaks sites which met at least two-thirds of their original target number for carers supported (Bristol, Hertfordshire, Suffolk, Torbay) all included carers' organisations in their partnership (see Chapter 4, Table 4.2).

[30] The Northumberland Care Trust was already a partnership engaging both health and social care organisations.

All NHS Support sites were led by an NHS organisation (Appendix C, Table C3), although in two cases the lead organisation's role was restricted to management of the project and did not include direct delivery of the additional support (Bolton, Halton and St Helens). All except one NHS Support site included at least one carers' organisation in its partnership, with carers' organisations contributing either by providing a specific service (e.g. carer awareness training / training about carers, as in the Northamptonshire, SW Essex and West Kent sites) or in delivering services, often providing staff, facilities or specific services to carers (Halton and St Helens, Hastings and Rother, Northamptonshire, SW Essex, Swindon, West Kent), with varying degrees of success. This approach was employed at the Halton and St Helens and Hastings and Rother sites, where both achieved high delivery numbers, but the Northamptonshire site was less successful in achieving delivery targets using this approach. Four sites also drew other voluntary sector organisations into their partnerships (Bolton, Hastings and Rother, Northamptonshire, Swindon), and again this met with mixed results.

All NHS Support sites included one or more local authorities as partners and most also had additional NHS partners, including hospitals and primary care staff (as well as the lead organisation). In several cases, these partners played a mainly advisory role, such as participating in the steering group (Bolton, Halton and St Helens, Swindon). Others worked on improving carer pathways or provided the settings in which other programme partners could work (Halton and St Helens, Northamptonshire, Swindon, West Kent). In one case a local authority was involved in raising awareness about carers and appointed its own 'carer champions' (SW Essex). Partnerships with local authorities also included work on improving Carer's Assessment procedures, documentation and delivery (Bolton, SW Essex, Swindon, West Kent).

In addition to the formal partnerships established through DS activity, case study staff also discussed the informal networks of organisations they developed through the programme, which involved other organisations without giving them a central role in the site's planning and organisation of the DS activities. Informal networks were often drawn upon as a way of establishing new referral pathways to meet carers' needs (e.g. voluntary sector organisations specialising in certain medical conditions were involved to help carers of those with these conditions). This approach was often used in the NHS Support sites. Informal networks also played an important role in identifying carers, assisting with DS marketing and (less commonly) delivering carer awareness training to DS staff. The East Sussex Breaks site offers an example of using an informal network to identify carers in the locality and deliver specialised short-term respite for carers of people with dementia / mental ill health. Similarly, in the Camden Health Checks site an informal network worked well as a way of signposting carers with a wide range of different needs to appropriate support.

Benefits of partnership working

All sites set up steering groups or 'project boards' which met regularly to discuss developments and progress, with the active representation of many key partners. This enabled staff in participating organisations to contribute to the design and delivery of activities and gave individual staff opportunities to work directly with colleagues in other organisations, often face-to-face. Many staff reported that the partnerships formed to deliver the DS programme represented a marked improvement on previous practice, noting that joint working in the past had often been impersonal and conducted mainly by phone or email. Over 50% of respondents in the Key Actor Survey reported that partnerships had improved as a result of the DS programme. Staff in voluntary organisations were particularly positive about the direct, face-to-face contact involved in the DS partnerships and the improved care co-ordination which they felt resulted. An example of how forming partnerships helped deliver enhanced support to carers (in one of the NHS Support sites) is provided in Box 3.2.

Staff interviewed as part of the national evaluation study often mentioned that bringing together different organisations also brought new skills, expertise and perspectives to programme design and delivery. Many felt this had led to a stronger programme, in which different organisations made unique

or distinctive contributions. In a Breaks site supporting carers through the provision of funding for equipment and domestic goods (Sunderland), a member of staff stressed that while local authorities and PCTs bring strategic perspectives to projects of this type, voluntary sector organisations often provide 'the practical bit' – information and 'know-how' about how to deliver projects in communities. In this Breaks site, for example, the lead organisation – a local authority – had designed the site's activities with the personalisation agenda firmly in mind. It aimed to provide a flexible service offering carers new kinds of breaks, matched to their personal circumstances, frequently in the form of a cash payment (to enable the carer to purchase something beneficial to their situation). This site found it much easier to deliver this service through the local carers' centre, as this avoided the complexities of making cash payments to individuals using local authority systems which were considered more bureaucratic and cumbersome.

Box 3.2 Improved care co-ordination in a NHS support site

The NHS Support site in Bolton (delivering a range of services including befriending and peer support, and new ways of offering Carer's Assessments) brought together a PCT, the local carers' centre and 23 local GP practices in an attempt to get these groups 'talking to one another' in a new way. In this site, partners found they were running complementary schemes and quickly decided that each partner could benefit from a closer working relationship, including sharing lists of registered clients. The result was greater system responsiveness, with carers identified through GP practices; benefiting from more systematic signposting between organisations; provided with information through websites, telephone help lines, and cross-agency databases; and given access to a social enterprise centre at which carers could meet and socialise, receive help and support on training, and use the Internet and access information. Improved care co-ordination was also achieved through joint commissioning of respite and sitting services by the PCT and the local authority.

Source: Site documents from the Bolton NHS Support site.

The DS programme was developed in part to explore new ways of reaching out to carers who were not previously receiving the support they needed. In their bids for DS funding, sites had pledged to provide services for carers in new and better ways, and most were keen to draw on the expertise of local organisations with knowledge of carers, or in contact with carer groups they were targeting. Strong partnerships were an effective way of addressing these goals. Many staff in the 'lead' organisations in the sites (local authorities and PCTs) felt working with or through voluntary groups was essential to achieve this, often mentioning that, in their view, carers 'preferred' to access services delivered through voluntary sector agencies[31]. Several case study interviewees referred to carers' concerns about engaging with 'official' organisations (e.g. social services) and potentially 'losing control'. In one Breaks site offering well-being support / services (Bristol), the formation of a partnership with a specialist voluntary group had helped engage with a number of ethnic minority communities resulting in support for carers that may not have been possible without this approach.

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[31] This was a fairly widespread belief, although evidence on this point was rarely offered. The Nottinghamshire local evaluation report included relevant evidence from work with Gypsies and Travellers. Some case study staff working in voluntary organisations mentioned that they felt carers' 'concerns' about 'official' organisations might, in the future, be transferred to voluntary groups if these became the main vehicle for delivering carer support.

Another Breaks site (Suffolk) drew on partnerships it had established with voluntary sector organisations to recruit and train carers to 'find' other carers, achieving considerable success in meeting target numbers and engaging with new carers. These 'carer recruiters' subsequently formed the basis of a new local carers' organisation, which was able to continue elements of the programme after the DS funding ended.

Many other partnerships established as part of the DS programme enabled sites to access carers previously not in touch with support services:

• One Health Checks site (Northumberland), based in a rural area, worked with a number of organisations across the locality to reach out to carers in remote districts, principally by using trained staff to provide health checks at home. This approach overcame the difficulty some carers living in remote areas had in attending NHS venues distant from their homes, and was popular and successful with carers accessing the service.

• One Breaks site (Torbay) offering equipment and domestic goods funding established partnerships with organisations not usually involved in carer services. Working with a local college, for instance, led to successful support activities for young carers, offering one-off payments to purchase items to help them in, or to get a break from, their caring role.

Partnerships also helped sites develop new ways of delivering services that complemented or improved existing models of carer support. For example, one Breaks site focused on improving access to breaks (Hertfordshire) formed a partnership with another organisation to develop an online booking system (to enable carers to take more control of their own breaks) on its behalf. This created a flexible alternative to booking breaks by telephone, as used in the past, and improved system responsiveness for carers who used it. The partnerships enabled some sites to deliver different components of their service through appropriate organisations in other sectors. In one Health Checks site (Redbridge) a health service provider with 'APO'[32] status was enlisted to deliver health checks while a voluntary organisation delivered well-being checks. Staff claimed pooling the expertise of these organisations benefited carers as they came into contact with the health and voluntary sectors through the same contact, maximising their access to support and offering a better co-ordinated service.

In an NHS Support site (Halton and St Helens), care co-ordination and system responsiveness were improved by a partnership through which voluntary sector staff (from a carers' centre) were based in a hospital (and assigned NHS email addresses). These staff approached carers attending hospital appointments who were not in touch with other services, providing them with support and advice and signposting them to the health checks programme. Staff in the carers' centre and the hospital felt they had benefited from this unprecedented opportunity to work together. Further examples of how DS partnerships led to improvements in care co-ordination and system responsiveness are presented in Table 3.1.

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[32] An APO (Autonomous Provider Organisation) is an organisation capable of, but not presently, operating independently from its host PCT and which works together with the PCT to provide community health services.

**Table 3.1 Impact of DS partnerships on social
            care system: examples of good practice**

Care co-ordination

- A multi-agency panel made decisions about access to DS support for carers. This allowed carers' organisations and local authorities to gain a better understanding of each other's perspectives, overcoming previous tensions, and enabled more effective cross-sector services – *Breaks site delivering equipment and domestic goods funding (Sunderland).*

- Carers coming forward for well-being checks who had not had a Carer's Assessment could be signposted to relevant resources in the local authority for this – *Health Checks site (Redbridge).*

- Delivering health checks together, voluntary organisations gained confidence in the PCT's approach to carers. Previous assumptions that carers were not part of their service delivery agenda were corrected, resulting in better co-ordinated activities – *Health Checks site focused on improving access to the service (Trafford).*

- The DS activity enabled local partners to 'map' existing referral networks in one locality, identifying which were working well and addressing problems in those which were less successful – *Health Checks site (Camden).*

- Involving a carers' steering group in decision-making about local authority carers' services enabled carer support workers based at a hospital to gain a better understanding of carers' needs – *NHS Support site delivering a wide range of services (Hastings and Rother).*

System responsiveness

- Working with a specialist organisation raised awareness about dementia patients in voluntary organisations which had previously been reluctant to deliver services to this group. Appropriate staff training for those providing this support was developed – *Breaks site delivering specialised short-term respite for carers of people with dementia / mental ill health (East Sussex).*

- Voluntary groups adopted 'whole family assessment' procedures in delivering services, improving on the patient-focused approach previously used by NHS organisations – *Breaks site delivering carers' holidays breaks (Bristol).*

- Working with voluntary groups, carers could use self-assessment procedures (without accessing local authority pathways, which some preferred not to use) – *Breaks site focused on delivering improved access to this services (Torbay).*

- A specialist voluntary organisation provided alternative care, including auxiliary nurses permitted to administer medication. This enabled some carers to access support without the person they cared for, which had not previously been possible – *Health Checks site focused on delivering improved access to this service (Trafford).*

- In one locality, several local authorities worked together to co-ordinate carers' access to Carer's Assessments. Identical forms and a single assessment procedure were mainstreamed across each local authority, cutting application processing times – *NHS Support delivering Primary Care based carer support and Carer's Assessments (South West Essex).*

Source: case study interviews, local evaluation reports

Many sites attempted to form partnerships with GP practices and hospitals, as staff felt carers could be engaged through organisations which dealt with patients daily and would be able to register carers and signpost them to other services. Some sites, of all three types, succeeded from the outset in establishing partnerships with GP practices and hospitals. They often had well-established relationships or previous collaborations with health partners which were strengthened or developed through the DS programme. Some of the local authority-led partnerships were engaging with GPs and hospitals for the first time, however, and had targeted PCTs as partners because staff felt there would be opportunities to share knowledge and negotiate improved arrangements with GPs and hospitals.

Although the numbers of carers referred for support through GP practices were at first modest, many sites found that as their site's work developed, GPs took a more active role and the number of referrals through GPs increased. Staff in some sites reported that, by the end of the delivery period, many GPs had seen the advantages of referring carers for support and that GP practices had become an important way of getting in touch with carers. The sites with most success with GPs adopted specific strategies to develop the role of GP practices in delivering support to carers, and one site's approach to effective working with GPs is shown in Box 3.3.

Box 3.3 Engaging GPs in innovative ways

Staff in Derby, a local authority-led site delivering a wide range of Breaks services (including alternative care in the home and well-being support/services), anticipated difficulties in engaging with GPs and took several steps to facilitate effective co-operation, including:

Recruiting a PCT development worker to negotiate with GP practices. This proved very effective and staff in this site wished they had done this earlier.

Appointing 20 'carer champions', with existing staff in 32 local GP practices allocated this role. The champions provided information and drop-in advice sessions for carers attending appointments, either when visiting a GP alone or when attending with the person they cared for.

Arranging regular network meetings, including staff from all organisations involved in delivering the DS programme, through which carer awareness could improve and knowledge and experiences could be shared.

Running awareness-raising sessions for GPs and health workers, including developing an online toolkit they could use.

Creating an electronic referral system for GPs to use when referring carers to the Breaks service. This was implemented successfully and included a 'feedback mechanism' informing the relevant GP of the outcome of any referral.

Source: site documents from the Derby Breaks site.

Another Health Checks site (Devon) experimented with a particularly wide variety of health service delivery partners, including GP practices, local pharmacies and St. John's Ambulance staff. Some aspects of this worked well. Partnerships with GP practices and St John's ambulance were effective in delivering health checks and engaging carers. The partnership with pharmacies was less successful, however, despite considerable efforts to support pharmacies to identify and engage carers.

Differences in partnership formation and arrangements do not fully explain different experiences and outcomes in each site. Sites successful in achieving their target numbers and reaching target groups of carers were slightly more likely to have pre-existing relationships with partner organisations. Several sites which struggled with these aspects experienced problems in engaging partners (although this was also true of some more 'successful' sites). Staff in most sites spoke enthusiastically about the DS partnerships and felt this aspect of the programme had been important for their wider activities and future plans for providing support to carers.

The DS partnerships certainly increased the local 'visibility' of many lead organisations. In one of the Health Checks sites (Northumberland, which was led by a Care Trust) a staff member pointed out that the health system was a *'big world'*. The Trust felt it had gained a higher profile with other organisations and new carers through its DS partnership, with likely benefits for future projects.

Some organisations worked together so well in the DS programme that staff felt there were benefits for other collaborative projects and a genuine prospect of better co-ordination of local support for carers. The importance of better understanding of other health and social care organisations and the way they operated, and greater knowledge of what they could bring to carer support were emphasised in one Health Checks site (Redbridge, led by a local authority). Staff described the DS programme as a *'first opportunity'* to work with health organisations, and a positive experience, with valuable learning for the local authority about how PCTs and GP practices work which would be beneficial in designing and implementing future collaborative projects of benefit to carers. In all three types of site, 'increased knowledge of other health and social care organisations', through partnership working, was reported by more than 50% of respondents to the key actor survey.

Difficulties in forming and operationalising partnerships

Despite the strong emphasis on the benefits of partnership working in the evaluation study, some sites experienced difficulties:

- Some complexities arose in running a single programme across organisations with different financial, management, staff and ethical policies and procedures. Sharing IT processes (e.g. a breaks booking service) across sites was a challenge as not all organisations had equivalent equipment or adequately trained staff. In these sites, tensions, ad hoc adaptation to procedures, complications and delays tended to result.

- Some organisations were difficult to engage. Staff at one NHS Support site delivering primary care based carer support (Hastings and Rother) noted that some hospital staff were more receptive than staff in GP practices and PCTs, perhaps because hospital staff had already received carer awareness training. One Health Checks site (Trafford) found organisations were at first reluctant to participate, fearing the programme would generate more demand for services than they could meet. The lesson here, staff claimed, was that it was necessary to 'sign up' partners prior to developing the programme.

- Some local organisations approached feared carers affiliated to them would be drawn away or 'poached'. Some had spent years building up a client group of carers and felt they needed to retain 'ownership' of it to support competitive bids for funding (this difficulty was commonly overcome through negotiation by experienced DS staff).

Across all three types of site difficulties were encountered in working with some GPs and getting them to agree to register carers or signpost them to other support. Some GPs were interested in the support needs of carers, and willing to engage in the DS programme, but others were not. One Health Checks site (Trafford) spent a lot of time in the early months of the DS programme trying to establish partnerships with GP practices but became frustrated at the extent to which interest in working with

carers varied from one GP practice to another. While the reasons for a lack of commitment to the DS programme among (some) GPs were sometimes unclear, staff in this Health Checks site summarised their experiences as follows:

- Many GPs adopted a narrow clinical focus, prioritising the needs of the patient rather than providing a 'holistic' service which included working with carers.

- Some GPs lacked the resources to provide emotional support and information to carers.

- GPs had concerns about increased workloads if supporting carers was added to their role.

Some sites attempted to overcome these problems by highlighting the longer-term benefits GP practices would gain by focusing on carers; both health benefits and fewer GP visits. These approaches had mixed results. Some GPs 'signed up' to the DS programme, but it was difficult to engage with others.

3.4   Impact on other carers' services

Prior to the DS programme, staff in many sites had been active in providing support to carers, delivering a range of services through local authorities, voluntary sector organisations and, in fewer cases, health settings. For many sites, the DS programme had been used to develop existing services, adapting projects already in operation, including some breaks services and health checks schemes, and (to a lesser degree) improving NHS support in the form of carer awareness training for clinical staff. Most sites had also added considerably to existing carer support, with services developed through the DS programme.

Local carers' strategies (usually developed by a local authority in consultation or partnership with other organisations) were already in place in some sites when the DS programme began, and where this was the case there was already a strategic, local approach through which many of the goals set for carer support at the national level were being pursued. Examples include a Health Checks site (Northumberland) in a rural area which had identified many older carers and was already trying to develop appropriate support for this group, and a Breaks site (Bristol) in an area with a large black and minority ethnic population, where a key element of the local carers' strategy was to improve support for carers in this community.

Not surprisingly, therefore, some sites had applied for DS funding because key staff saw it as an opportunity to 'fast track' existing delivery plans for carer support. Staff in many sites reported that the DS programme had enabled their organisation to progress strategic goals which it had previously been impossible to implement as no funding was available. In these sites, the DS programme made their plans possible but did not fundamentally re-shape their approach. As one member of staff in a Breaks site focused on improving access to breaks explained, *'very often, what you have is a lot of lovely policy – but if you haven't got a mechanism, it's not possible to do anything'.*

In many of the sites that had used the DS programme to develop existing carer support, staff reported that previous services had tended to be limited and rigid, with little flexibility of implementation. Many staff in these sites reported that the DS programme, by contrast, was characterised by its flexible, personalised nature, and was a welcome opportunity to develop previous services along these lines. One carer development worker based at a voluntary organisation described an existing respite service in relation to the new DS Breaks service provided by the site:

> *The existing service was of a very similar ilk, but very narrow in its scope. It was often people who were at the very end of their caring role as they were elderly and so on. Whereas the scope of this project has meant they can really look at the community in its wider sense and enable it to be not just about giving money, rather using funding in a very different way.*

For other sites, however, the DS funding opportunity led to an unprecedented focus on carer support. Thus in one of the NHS Support sites (Halton and St Helens), staff in the Primary Care Trust (which had the lead role) saw the programme as their chance to develop a new approach to carer support, claiming that only the local authority had been able to do this in the past. In this site the PCT's leadership led to a focus on the health needs of carers (something staff said had never been adequately addressed in the past).

Whether their overall approach was different or not, many sites reported that the DS funding gave them the opportunity to explore new ideas, deliver services more flexibly, and introduce 'personalisation' more quickly. Many site staff raised personalisation as a key issue when discussing their implementation of the DS programme. One interviewee reported that previously (in the locality), the personalisation agenda had been well implemented for *'service users'*, but not for carers. Staff in many sites felt the DS programme had provided an opportunity to address this, often drawing attention to the shortcomings of existing understandings of personalisation in the health and social care system as it affected carers. Some Breaks sites had previously offered personalised schemes (e.g. tailored breaks packages incorporating personal budgets) but felt that the DS programme had really allowed them to build upon and extend this previous work.

Thus for most sites, the DS programme had fitted into a range of existing carer-focused projects, understandings and aspirations, allowing them to expand services or to create new strands of support for carers which complemented their long-term plans. As discussed throughout this chapter, these modifications also led to changes in the way organisations delivered some services, including adjustments to the way staff operated and new or different ways of working with partner organisations. There is also evidence that, as a result of DS activity, many sites developed new ways of working that signified long-term organisational change leading to enhanced support for carers, including:

- Adapting carer support procedures. Examples include Carer's Assessments modified to include a health component and improved referral processes (including electronic systems) making carer services more system responsive.

- More extensive use of direct payments to provide flexible solutions to carers' needs.

- Adopting new database systems to register carers, providing more detailed knowledge of local carer groups and their support needs.

- Improved use of communication networks, including email and web-based applications, contributing to improved care co-ordination across different organisations.

- Using new evaluation instruments to demonstrate the efficacy of projects.

- Wider use of staff training to enhance carer support service delivery.

- Greater confidence and knowledge of bidding for funding in the social care field (including understanding budgetary arrangements).

Key Findings

This chapter has examined the impact of the Demonstrator Sites programme on staff and organisations. It has considered how the programme affected staff roles and partnerships, with particular reference to working relationships, the extent to which improved system responsiveness and care co-ordination resulted, and the impact on carer services.

• Impacts on staff involved in delivering the DS programme took a number of forms, many of which were common across all three types of site, including increased workloads, improved teamwork, greater carer awareness, engagement with carers not previously in touch with support services, and developing new skills.

• Some impacts on DS staff were specific to particular types of site, including some sites that needed to: work in different venues (e.g. carers' homes); deal with early difficulties in providing carer support (including benefiting from dedicated training); and overcome resistance among some staff in the health and social care sector to engage in new types of carers' services that differed from traditional approaches.

• Health and social care professionals (e.g. GPs and practice staff, social workers, and other local authority staff) had few problems in integrating DS activities into their existing roles. Voluntary sector staff experienced a significant increase in workload, but found engagement with the DS programme beneficial in terms of 'capacity building' within their organisations.

• Sites developed a variety of partnerships with other organisations, including voluntary sector groups, NHS organisations, and local authorities. Most partnerships were formally established as part of the DS programme, while others were developed as informal networks utilised when required, particularly to reach carer groups not previously in touch with support services.

• Benefits of DS partnership working included: drawing on the relative expertise of particular organisations in appropriate ways; engaging with carers not previously in touch with support services through specialist support groups; bringing together health and social care sectors to improve care co-ordination and system responsiveness; and working with GP practices and other NHS organisations (e.g. hospitals) to engage with carers identifiable through the health system.

• Some difficulties were encountered in partnership formation, including: restrictions arising from different organisational procedures and/or access to resources (e.g. IT systems); low levels of project commitment from some partners; variable levels of engagement by GPs; and some organisations fearing carers registered with them would be drawn away.

• The DS programme enabled sites to develop and / or progress long-term carer support objectives and to promote personalisation. Several new approaches to service delivery were established, including: improved carer support procedures; use of more advanced databases for monitoring carers and their support needs; improved communication networks across the health and social care system; and implementation of carer awareness training for staff.

Chapter 4
Innovative Approaches to Engaging and Involving Carers in Services and Support

Christina Buse and Andrea Wigfield

4.1   Introduction

Treating carers as 'expert care partners' was a strong theme in the National Carers' Strategy in 2008 and an approach strongly endorsed by the incoming Coalition Government, when, in November 2010, it identified four 'priority areas' for its policy on carers (with advice from the Standing Commission on Carers), listing the first of these as:

> *Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages.*
>
> *(HMG, 2010a:6)*

Despite their often intimate knowledge and experience of the needs of those they care for, and the importance to the health and social care system of the care they give, a large body of research has shown that carers: do not always feel recognised or valued by health and social care professionals; are sometimes reluctant to seek help; may feel isolated, unsupported and alone; and can sometimes be completely 'hidden' from those responsible for planning and delivering health and social care services (Graham 1985; Henderson, 2001; Stiell *et al* 2006; O'Conner, 2007; Yeandle *et al*, 2007a).

These circumstances can arise for many different reasons: some do not see themselves as a 'carer' (or do not wish to accept this label), or may care for someone who is reluctant to make contact with service providers; others are unaware of available support and services and how to access them, or feel they would not be eligible for assistance; some feel their understanding or knowledge of the person they care for has been (or would be) disregarded or dismissed by professionals, or that they have been excluded from decisions about their caring role.

Identifying oneself as a carer is also bound up with values and attitudes which can be deeply personal, shaped by cultural expectations and beliefs about family responsibility and gender, or influenced by feelings of obligation, responsibility, duty and love (Qureshi and Walker, 1988; Finch and Mason, 1993). Carers in some circumstances, or with some characteristics, are especially likely to be unrecognised or to be 'hidden' in the sense that they do not perceive themselves as carers or are unknown to service providers. There is evidence that carers in some ethnic minority or faith groups, young carers and carers of people with some health conditions are especially likely to be in this situation (Perry et al, 2001; Harper and Levin, 2005; Yeandle *et al*, 2007b; Smyth *et al*, 2011).

Against this background of knowledge, and in the context of the wider aims of the National Carers' Strategy, establishing new and innovative ways to identify carers, engage them in the services offered, and actively involve them in designing, delivering and evaluating carer support were some of the most important objectives of the DS programme as set out in the prospectus inviting bids for funding (DH, 2009). The prospectus indicated that, when bidding for funding, sites should demonstrate their approach to identifying 'under-reached' carers, as well as how they planned to satisfy carers' unmet needs. Many of the bids received incorporated plans to achieve this, and some outlined their aims to identify specific groups of carers which they felt were particularly 'under-reached' (such as ethnic minority, younger or older carers; carers of people with mental ill-health or substance misuse problems).

This chapter examines a number of key issues: the overall numbers of carers and the specific groups of carers sites aimed to engage with and involve; the approaches adopted by the sites to achieve this; and the relative success of the different approaches. Evidence is drawn from the case study interviews, quarterly calls, documentary analysis and management information. Section 4.2 examines how far the sites were successful in engaging with carers both generally, and with the target groups specifically. This is followed by a discussion of the relative strengths of the different approaches adopted by the sites to identify and engage carers (section 4.3). Section 4.4 examines the type and levels of carer involvement in service design, delivery and evaluation, exploring the benefits and challenges encountered by the sites. A summary of the key findings is then provided at the end of this chapter.

4.2   Engaging with carers

The 25 sites implementing the DS programme supported a total of 18,653 carers during the programme delivery phase (5,655 in Carers' Breaks sites; 5,441 in Health Checks sites; and 7,557 in NHS Support sites); an additional 28,899 carers were contacted[33] by the sites but did not receive services (Table 4.1). Most sites estimated the numbers of carers they expected or aimed to engage with, regularly monitoring the numbers of carers accessing the support services at steering group meetings and analysing management information. The original target numbers for carers set by the sites varied substantially, however, both between types of site and between sites of the same type, as shown in Tables 4.2, 4.3 and 4.4.

Engaging with carers in Breaks sites

The different definitions of a break used in the Breaks sites led to wide variations in the volume of breaks reported (Table 4.2), and with each site setting its own definition of a break, the figures for different sites cannot be compared directly. The Breaks sites, overall, delivered (using their own definitions) over 30,000 breaks[34], although it is not clear how many of these breaks would have been booked anyway without the assistance of such staff or the existence of the DS programme.

Table 4.1 Number of carers supported, by type of site

Site type	Number of carers contacted	Number of carers supported
Carers' Breaks	13,844	5,655
Health Checks	22,070	5,441
NHS Support	11,638	7,557
Total	**47, 552**	**18,653**

Source: QRTs.

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[33] Many sites used mass marketing techniques, contacting large numbers of carers in this way. Those contacted did not necessarily take up services.

[34] With the exception of the Liverpool site, all sites defined 'breaks' in ways which meant that carers who received more than one break as defined by the site (as many did) were counted repeatedly in the 'breaks services delivered' numbers. In East Sussex for example, site documents made it clear that a 'break' was defined as alternative care provision for 2.5 hours. If the person cared for attended a day centre (or similar service) for five hours (for example) this was recorded as the carer having two breaks. In sites where carers used personal budgets to purchase goods or services (laptops, gym memberships, etc.), each item purchased counted as one break (even if used many times over a prolonged period).

In Breaks sites, expected numbers of carers varied from 100 in the Warwickshire site to 8,320 in the East Sussex site (Table 4.2). Most sites reported 'contacting' many more carers than were actually supported through the DS breaks service[35], a pattern which was similar for the Health Checks and NHS Support sites and which was partly an outcome of the marketing methods used, and very varied expenditure on marketing (discussed later).

The numbers of carers supported through the Breaks provision ranged from just 25 in the Warwickshire site to 915 in the Derby site. Three sites (Bristol, Hertfordshire and Suffolk) came close to (or exceeded) their original aims for numbers of carers supported. Most, however, found it difficult to deliver support to as many carers as they had hoped to engage (the Derby site, for example, which engaged 915 carers, more than any other Breaks site, originally aimed to support over 2,000 carers). The numbers of carers supported in each site should also be compared with the site's total spending, an issue explored in Chapter 6.

Of the nine sites where the percentage of 'new' (previously unknown) carers supported could be calculated (Table 4.2), five reported providing services exclusively to carers who had not previously been in contact with them (Bath and NE Somerset, East Sussex, Lewisham, Sunderland and Warwickshire). In the East Sussex and Lewisham sites, carers were referred to the service by other agencies or departments, and in Warwickshire (where challenges in engaging carers were encountered) some carers were contacted directly and offered the service.

Only seven sites reported a figure for the number of carers accessing the alternative care which sites provided, or made available, to enable them to access a break. Apart from sites in which alternative care was the main model of breaks provision (as in the East Sussex site[36]), the Lewisham site provided alternative care to the highest proportion of carers supported (58%). Many other sites reported that 'take-up' of alternative care was much lower than expected.

Engaging with carers in Health Checks sites

The Health Checks sites overall delivered a total of 5,438 health checks. In the Health Checks sites, expected numbers of carers varied from 600 in the Redbridge site to 3,000 in the Devon site (Table 4.3). Each site established its own definition of what counted as 'contact' with a carer and most sites reported that they contacted many more carers than actually took up the offer of a health check (with the exception of the Tower Hamlets site). In the Redbridge site (where carer health checks were targeted using a stratification tool[37]) the number of carers contacted who did not take up the offer of a health check was much lower than in other sites. The numbers of carers supported through the health checks provision ranged from 268 in the Camden site to 2,924 in the Devon site. Just two sites (Devon and Redbridge) came close to (or met) their original aims for numbers of carers supported. The other four sites found it difficult to deliver support to as many carers as they had hoped to engage (the Camden site, for example, aimed to support 1,890 carers but achieved only 14% of that number (268 carers). The Devon site delivered five times more health checks than any other site (2,924 checks) but, because its model involved annual review, completed only 105 follow-up checks before the end of the DS programme. By contrast, the Redbridge, Tower Hamlets and Trafford sites all delivered most or all of their planned follow-up checks within the lifetime of the programme. This affected the amount of

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[35] Definition of 'contact' with a carer was made by sites. Some may have counted only face-to-face contact while others may have counted carers who were sent a leaflet or attended a carers' event.

[36] The breaks provision in this site mainly involved Carer Support Workers (CSWs) working closely with the person cared for, to engage them in meaningful activities which enabled the carer to take a break, reassured that they were being well looked after. These activities included one-to-one support for the person cared for and / or their carer in the community and in group activities (including exercise, dance, entertainment and art therapies)

[37] This tool was used to identify carers or persons cared for who were at risk of admission to hospital. Carers identified were then approached and offered a check, and were therefore recruited in a rather different way than carers who responded to a marketing / advertising campaign.

Table 4.2 Carers' Breaks sites: number and types of carers supported and breaks delivered

Site	Approach to Breaks provision see KEY 1	Expected number of carers	Breaks delivered number	Carers contacted number	Carers supported number	Carers previously unknown %	Target number achieved %	Target groups mentioned in bid see KEY 2	Target groups reached[1] see KEY 2	Carers using alternative care number (%)
Bath and NE Somerset	B, C, E, F, G, H, I, J	1,600	2,843	438	438	100	36	B, DC, M, R, Y	B,DC, M	26 (6)
Bristol	B, C, D, E, F, G, H, I, J	900	1,039	3,505	756	#	84	B, H, P, Y	B, P	16 (2)
Derby	B, C, E, J	2,080	1,060	1,670	915	45	45	D	*	130 (14)
East Sussex	A	8,320	13,868	620	605	100	7	AD, B, D, LG, M, R	D, M	605 (100)
Hertfordshire	B, J	348	6,650	1,912	689	35	198	B, L, M, O, PD, SF	B, O	#
Lewisham	B, C, D, E, G, I	400	158	170	100	100	25	B, D	D	58 (58)
Liverpool	B, C, E, H, I, J	600	266	391	266	55	44	B	B	0
Nottinghamshire	A, B, C	6,768	3,517	980	708	51	10	B, C, D, G, L, PD, R	B, D, PD	35 (5)
Suffolk	B, C, D, E, F, G, H, I, J	550	757	663	509	70	92	AD, B, D, L, LG, Y	B, LG	100 (20)
Sunderland	B, C, E, F, G, H, I, J	1,000	590	573	389	100	39	n/a	n/a	#
Torbay	B, E, I, J	393	#	644	255	#	65	AD, B, D, O, SF, Y	D, O, Y	0
Warwickshire	B, J	100	#	2,278	25	100	25	L	*	0

KEY 1: Approaches to Breaks provision:

A. Specialised short term respite
B. Alternative care in the home
C. Carers' holiday breaks funding
D. Practicing help in everyday life
E. Well-being support / services
F. Training for the caring role
G. Work related training
H. Training for other skills
I. Equipment and domestic goods funding
J. Improving access to breaks

KEY 2: Target Groups:

A: Carers of people with aggressive/unsociable behaviour
AD: Carers in areas of deprivation
B: BME carers
BR: Bereaved carers / carers of people nearing end of life
C: Carers of people with complex conditions not elsewhere specified
D: Carers of people with dementia
DC: Disabled carers
G: Gypsy and Traveller carers
H: Carers in areas of high health inequalities
HIV: Carers of people with HIV / aids
L: Carers of people with learning disabilities
LG: LGBT carers
LTC: Carers of people with long term conditions

M: Carers of people with mental ill health
MA: Male carers
O: Older carers
P: Parent carers
PD: Carers of people with physical disabilities
R: Rurally isolated carers
ROA: Carers of people at high risk of hospital admission
S: Carers of people with substance misuse problems
SD: Carers of people with sensory disabilities
SF: Self-funding carers
Y: Young carers
W: Workforce / working carers

Sources: case study interviews, ICRs, local evaluation reports, site documents, QRTs, quarterly calls, DH management information.
Notes: # Data not supplied by site; * Insufficient evidence available. [1]Based on data from the local evaluation reports and ICRs.

Table 4.3 Health Checks sites: number and types of carers supported and health checks delivered

Site	Approach to Health Checks provision see KEY 1	Expected number of carers	Carers contacted number	Carers supported number	Target number achieved %	Health checks delivered number	Target groups mentioned in bid see KEY 2	Target groups reached[1] see KEY 2	Carers using alternative care number (%)
Camden	A, B, C	1,890	597	268	14	268	AD, B, BR, H, L, S, SF, Y	B, Y, L	11 (4)
Devon	A,B,C	3,000	11,863	2,924	97	2,924	A, B, BR, C, D, HIV, LG, LTC, MA, O, P, R, SD, W, Y	O, M, D, SD Y, B, R, P, W, LTC	10 (0.3)
Northumberland	A, B, C	2,250	3,020	457	20	457	B, C, O, R, S	O	7 (2)
Redbridge	A, B, C	600	679	600	100	600	B, BR, L, LTC, P, ROA, S, W, Y	B, O, ROA, LTC, P	0 (0)
Tower Hamlets	A, B, C	1,800	605	605	32	605	B, BR, D, L, LTC, M, P, PD, S, SD, Y	B, Y, SD	60 (10)
Trafford	A,B,C	1,200	5,306	587	49	587	AD, B, C, D, H, O, S	*	56 (10)

KEY 1: Approaches to Health Checks provision:

A. Physical health examination
B. Well-being check
C. Accessibility of Health checks

KEY 2: Target Groups:

A: Carers of people with aggressive / unsociable behaviour
AD: Carers in areas of deprivation
B: BME carers
BR: Bereaved carers / carers of people nearing end of life
C: Carers of people with complex conditions not elsewhere specified
D: Carers of people with dementia
DC: Disabled carers
G: Gypsy and Traveller carers
H: Carers in areas of high health inequalities
HIV: Carers of people with HIV / aids
L: Carers of people with learning disabilities
LG: LGBT carers

LTC: Carers of people with long term conditions
M: Carers of people with mental ill health
MA: Male carers
O: Older carers
P: Parent carers
PD: Carers of people with physical disabilities
R: Rurally isolated carers
ROA: Carers of people at high risk of hospital admission
S: Carers of people with substance misuse problems
SD: Carers of people with sensory disabilities
SF: Self-funding carers
Y: Young carers
W: Workforce / working carers

Sources: case study interviews, ICRs, local evaluation reports, site documents, QRTs, quarterly calls, DH management information.
Notes: # Data not supplied by site; * Insufficient evidence available. ¹Based on data from the local evaluation reports and ICRs.

Table 4.4 NHS Support sites: number and types of carers supported

Site	Approach to NHS Support see KEY 1	Expected number of carers	Carers contacted number	Carers supported number	Carers identified (previously unknown to site) number	Target number achieved %	Target groups mentioned in bid see KEY 2	Target groups reached[1] see KEY 2	Carers using alternative care number (%)
Bolton	C, D, E, F	1,413	885	785	423	56	B, O, D, M, Y	D, M, Y, B, O	0 (0)
Halton and St. Helens	A, B, D, E	4,600	3,510	3,510	3,510	76	B, BR, LTC, W,	W	0 (0)
Hastings and Rother	A, B, C, D, E	600	1265	1,060	1,277	177	AD, B, G, H, MA, R, Y	*	0 (0)
Northamptonshire	B, C, D, E, F	1,200	4,006	554	360	46	B, LTC, M, Y	LTC	0 (0)
South West Essex	A, B, D, E, F	524	452	450	452	86	B, D, L, M, O, Y	M, D	0 (0)
Swindon	A, C, D, E, F	100	940	618	714	618	B, D, M, Y	B, M	23 (4)
West Kent	A, B, D, E, F	150	580	580	580	387	AD, B, G, L, M	B, L	#

KEY 1: Approaches to NHS Support provision:

A. Hospital based carer support
B. Primary Care based carer support
C. Voluntary sector based carer support
D. Carer awareness training NHS staff
E. Information about carers / information for carers
F. Carer assessments: delivery and / or documentation

KEY 2: Target Groups:

A: Carers of people with aggressive / unsociable behaviour
AD: Carers in areas of deprivation
B: BME carers
BR: Bereaved carers / carers of people nearing end of life
C: Carers of people with complex conditions not elsewhere specified
D: Carers of people with dementia
DC: Disabled carers
G: Gypsy and Traveller carers
H: Carers in areas of high health inequalities
HIV: Carers of people with HIV / aids
L: Carers of people with learning disabilities
LG: LGBT carers

LTC: Carers of people with long term conditions
M: Carers of people with mental ill health
MA: Male carers
O: Older carers
P: Parent carers
PD: Carers of people with physical disabilities
R: Rurally isolated carers
ROA: Carers of people at high risk of hospital admission
S: Carers of people with substance misuse problems
SD: Carers of people with sensory disabilities
SF: Self-funding carers
Y: Young carers
W: Workforce / working carers

Sources: case study interviews, ICRs, local evaluation reports, site documents, QRTs, quarterly calls.
Notes: # Data not supplied by site; * Insufficient evidence available. [1] Based on data from the local evaluation reports and ICRs.

activity reported in each site, but also raises questions about desirable practice. The local evaluation of the Devon site recommended that, to support carers in the best possible way, health checks should be followed up at six months (with a half hour appointment). As with the Breaks sites, the numbers of carers supported in each site should also be compared with the site's total spending (see Chapter 6).

The Health Checks sites provided alternative care to allow carers to access health checks (and other medical appointments), if the need for alternative care to attend appointments was identified in the physical health or well-being checks. All sites offered carers (or referred them to) funding for (and / or services to provide) alternative care. The number of carers accessing alternative care was lower than expected in most sites, however (and the Redbridge site reported that no carers opted to use alternative care, see Table 4.3[38]). The Tower Hamlets site, which had the highest number of carers accessing alternative care, explored an approach in which carers could pay family members or friends to 'cover' for them (or offer suitable support) rather than use an agency, care worker or personal assistant.

Engaging with carers in NHS Support sites

In NHS Support sites, expected numbers of carers varied from just 100 in the Swindon site to 4,600 in the Halton and St Helens site (Table 4.4). In the Northamptonshire site there was a marked difference between the number of carers contacted and supported[39], although in all other sites the number of carers supported was close to (or the same as) the number of carers contacted – a marked difference to experiences in both the Breaks and Health Checks sites. This difference arises primarily because the NHS Support sites engaged carers directly in health care settings such as hospitals and GP practices, while many of the Breaks and Health Checks sites used a range of other methods of contacting carers such as mail outs, advertisements, leaflets and posters. Numbers of carers supported through the NHS Support sites ranged from 450 in the South West Essex site to 3,510 in the Halton and St Helens site. Overall, NHS Support sites were more successful at meeting or exceeding their original target numbers of carers, with three sites (Hastings and Rother, Swindon and West Kent) exceeding their targets and a further two sites (Halton and St Helens and South West Essex) coming close. The Halton and St Helens site, which had an especially ambitious target for carer numbers, reached over 3,500 carers and the Hastings and Rother site, which supported over 1,000 carers, very significantly exceeded its more modest target of 600 carers. The Halton and St Helens site identified carers in hospitals, both as they came in for their own appointments and when they were accompanying the person they cared for. This meant initial contact with the site was always face-to-face and carers could be given some information about the service and referred to an appropriate team member at this point. As mentioned previously, the numbers of carers supported in each site should also be compared with the site's total spending (see Chapter 6). Many of the carers supported through the NHS Support sites were previously unknown to the sites (Table 4.4) and in total, 7,316 carers not previously known to sites were identified. Carers in only one site (Swindon) made use of alternative care and even there the numbers making use of this service were very low (4%). Alternative care was not generally offered or delivered directly as part of the main NHS Support services, as the carer support was generally provided in hospitals and GP practices, and did not usually involve leaving the person cared for (in contrast to the breaks and health checks services).

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[38] As with Breaks sites, it is not possible to refer to the 'take up' of alternative care as sites did not systematically monitor the way they offered this support or its uptake.

[39] Methods of engaging carers in the Northamptonshire site, which included using an existing carers' register and sending those listed on it a letter about the DS services, may account for some of this, as many carers who did not subsequently make contact with the site would have been sent a letter.

Successful engagement with carers: some explanations for success

When looking at the types of approaches adopted by sites and their degree of success in engaging with carers (Tables 4.2, 4.3 and 4.4), some interesting points emerge in both the Breaks and NHS support sites. Two of the Breaks sites which successfully reached relatively large numbers of carers (and almost met their initial targets – Bristol and Suffolk) both offered a highly personalised service and offered a wide variety of different types of breaks, suggesting that a choice of breaks is appealing to carers. In contrast, both the Hertfordshire and Warwickshire sites offered alternative care in the home and a new on-line booking system to improve and widen access to Breaks. However, as Table 4.2 shows, the outcomes in terms of numbers of carers supported varied substantially between these two sites, with the Hertfordshire site more than meeting its initial target numbers and supporting a large number of carers, while the Warwickshire site met just a quarter of its original target and supported only 25 carers. Potential explanations for these variations in performance are numerous: Hertfordshire tapped into databases of carers already using alternative care services, and provided support to carers using the new on-line booking system, while the Warwickshire site targeted previously 'unknown' carers of people with learning disabilities, who had not accessed alternative care before, and allowed carers to access the breaks provision through other off-line options.

Engaging with under-represented groups of carers

Sites attempted to reach under-represented carers by targeting specific groups. The target groups listed by sites in their original bids (summarised in Appendix B) included: ethnic minority carers (including Gypsies and Travellers as a separate group); carers of people with substance misuse problems; carers of people experiencing mental ill-health; carers of people with dementia; carers of people with learning and / or physical disabilities; young carers; older carers; rurally isolated carers; disabled carers; LGBT (Lesbian, Gay, Bi-sexual or Transgender) carers; parent carers and working carers. Most sites identified several different target groups in their bids (Tables 4.2, 4.3 and 4.4), with Health Checks sites targeting a particularly wide range of under-reached carers. All but two Breaks sites (Derby and Warwickshire) targeted ethnic minority carers and about half of all sites targeted carers of people with dementia and young carers (12/25 and 13/25 respectively). The Devon (Health Checks) and Hastings and Rother (NHS Support) sites were the only ones to target male carers, while only the East Sussex and Suffolk (Breaks) and Devon (Health Checks) sites targeted LGBT carers. Three sites targeted Gypsies and Travellers (Nottinghamshire, Breaks; Hastings and Rother and West Kent, NHS Support).

Often the choice of target groups reflected the specifications in the DH prospectus (DH, 2009:6), which stated that in commissioning the DS programme the DH was:

> *particularly interested in the development of ways to support carers who support people with complex needs such as older people with dementia, people with mental health problems, people with learning disabilities and additional needs, people with complex disabilities and of course young carers.*

The prospectus also stated that the DH *'welcomed bids reflecting the diversity of the local population and taking account of cultural and other preferences within the black and minority ethnic (BME) community'* (DH, 2009:6).

Explanations for the initial selection of target carer groups were not always provided in the bids, although in some cases (for example, East Sussex, Lewisham and Suffolk: Breaks; Devon and Redbridge: Health Checks; and Northamptonshire, Swindon, and West Kent: NHS Support) bids stated target groups had been chosen to ensure that carers supported would be representative of all carers in the locality.

The profile of carers supported by the sites was one of predominantly older, female carers (see Chapter 5). This may, in part, be explained by the fact that only two sites (Devon, Hastings and Rother) initially specified male carers as a target group and many sites targeted carers of people with dementia (who are often older people caring for a spouse).

Sites were largely successful in engaging with carers from ethnic minority communities and the Breaks and Health Checks sites were especially successful in targeting these carers (Tables 4.2 and 4.3). In three Health Checks sites the majority of carers supported were from ethnic minority communities (Table 4.5), Tower Hamlets (66%), Redbridge (55%), and Camden (53%), a reflection both of the steps taken in these sites to target these carers and of the composition of their local population. Carers of people experiencing dementia, mental ill-health, long-term / terminal illness, learning disabilities and substance misuse problems were also well represented in the sites (Table 4.5), when compared with the national profile of carers (see Chapter 5).

Some sites (Torbay, Breaks; Camden and Tower Hamlets, Health Checks; and Bolton, NHS Support) were successful at engaging with young adult carers aged 18-24 (Table 4.6), developing some specially targeted initiatives. One Breaks site (Torbay) developed a specific initiative for targeting young carers in creative ways, such as through Facebook, and working with young carers in colleges, and almost a fifth of carers supported were young adult carers (Table 4.6). In the Camden Health Checks site a similar initiative targeted young adult carers and here 12% of carers supported were aged 18-24 (Table 4.6). The local evaluation report for the Bolton NHS Support site reported that this site was also successful in engaging with young carers (under 18[40]), who were identified through work with specialist organisations such as Barnardos and by liaising with local schools, mental health teams, and in primary care settings.

Success in engaging with target groups varied between and within site types, however. The Breaks sites achieved success, or a degree of success, in their efforts to reach out more effectively to carers in nine different groups widely regarded as hard to reach (Table 4.2): carers in black and minority ethnic groups (six sites); carers of people with mental ill-health (two sites); carers of people with dementia (three sites); older carers (two sites); and young carers (one site).

The Breaks sites were particularly successful at engaging with carers of people with dementia (38% of all carers supported were carers of people with dementia, compared with 18% in Health Checks and 23% in NHS Support sites, Table 4.5). Two Breaks sites (East Sussex and Lewisham) identified many carers of people with dementia through hospital, community or social work teams. A similar pattern emerged in relation to carers of people experiencing mental ill-health; 45% of all carers supported in Breaks sites were carers of people experiencing mental ill-health, compared with 28% in NHS support sites and 17% in Health Checks sites. The Bolton site, which engaged with a high proportion of carers of people experiencing mental ill-health, was an NHS Support site led by a mental health trust and took referrals of carers from community and hospital teams.

At various points in the delivery period, the number of carers receiving breaks or other services, or engagement with particular target groups of carers, was lower than expected. In response to this, seven of the Breaks sites added new approaches to engaging with providers and carers or involved additional providers or organisations in delivery or engagement processes.

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[40] See Appendix A.1 for an explanation of why carers under 18 were not included in the national evaluation study

Table 4.5 Carers supported by Demonstrator Sites, by target groups %

Demonstrator Site	Carers		Carers of people with / experiencing				
	Male	BME*	Dementia	Mental ill health	Long term / terminal illness	Learning disability	Substance misuse
Carers' Breaks	**31**	**14**	**38**	**45**	**48**	**16**	**3**
Bath and NE Somerset	26	30	16	27	21	19	1
Bristol	25	11	28	29	40	25	2
Derby	51	6	12	17	76	9	2
East Sussex	37	13	94	88	74	1	1
Hertfordshire	13	50	67	13	20	9	0
Lewisham	27	10	93	0	3	0	0
Liverpool	29	22	19	49	30	33	2
Nottinghamshire	36	22	41	19	23	14	0
Suffolk	33	3	14	27	73	15	4
Sunderland	30	0	10	50	51	21	14
Torbay	32	0	35	26	22	7	1
Health Checks	**28**	**19**	**18**	**17**	**42**	**12**	**1**
Camden	23	53	21	34	36	24	5
Devon	29	2	21	17	43	11	1
Northumberland	31	0	21	17	42	7	2
Redbridge	26	55	16	7	71	18	1
Tower Hamlets	28	66	6	22	11	11	0
Trafford	16	14	0	14	2	24	2
NHS Support	**31**	**10**	**23**	**28**	**33**	**10**	**2**
Bolton	31	12	31	78	5	5	3
Northamptonshire	38	8	17	15	38	19	0
South West Essex	23	2	21	19	32	10	0
Swindon	27	19	11	26	41	17	2
West Kent	32	12	24	16	49	10	2
TOTAL (All sites)	**30**	**16**	**27**	**30**	**44**	**14**	**2**

Source: ICRs.
Notes: *BME refers to people from Black and Minority Ethnic communities.
Three sites (Halton and St Helens, Hastings and Rother and Warwickshire) are excluded from this table as the numbers of ICRs submitted by these sites were less than 5, or represented less than 5% of the total number of carers supported.

Table 4.6 Carers supported by Demonstrator Sites, by age   %

Demonstrator Site[1]	18-24	25-34	35-49	50-64	65-74	75+
Carers Breaks	**3**	**4**	**23**	**37**	**18**	**15**
Bath and NE Somerset	1	6	20	35	23	14
Bristol	4	6	31	31	12	17
Derby	0	2	10	27	27	35
East Sussex	0	0	5	18	27	50
Hertfordshire	0	0	7	36	18	39
Lewisham	0	0	38	0	25	38
Liverpool	4	3	21	45	19	8
Nottinghamshire	2	8	16	22	30	22
Sunderland	2	4	31	45	12	7
Torbay	18	4	9	34	18	17
Health Checks	**2**	**3**	**16**	**34**	**21**	**24**
Camden	12	8	28	34	9	9
Devon	0	1	13	36	24	26
Northumberland	0	1	7	30	26	37
Redbridge	0	20	10	50	0	20
Tower Hamlets	6	15	34	30	12	4
NHS Support	**1**	**4**	**18**	**43**	**18**	**16**
Bolton	1	3	19	43	21	13
Northamptonshire	0	6	18	39	18	18
South West Essex	0	5	25	51	12	7
Swindon	0	11	22	39	15	13.
West Kent	2	2	19	39	19	22
TOTAL (All sites)	**2**	**4**	**18**	**36**	**20**	**20**

Source: ICRs.
Notes: [1]Three sites (Halton and St Helens, Hastings and Rother and Warwickshire) are excluded from this table as the numbers of ICRs submitted by these sites were less than 5, or represented less than 5% of the total number of carers supported.

The Health Checks sites, together, targeted carers in many different groups which they considered difficult to reach or to contain 'under-reached' carers (Table 4.3). Most sites felt their work had been successful in relation to at least some of the groups they hoped to reach. Groups targeted effectively in at least some sites included: carers in black and minority ethnic communities (four sites); older carers (three sites); young carers (two sites); parent carers (two sites); carers of people with sensory disabilities (two sites); carers of people with dementia (one site); carers of people with learning disabilities (one site); carers of people with long-term conditions (two sites); rurally isolated carers (one site); and carers of people at high risk of admission to hospital (one site).

Some other sites tried to work with carers in these groups but were less successful, and there were a number of groups targeted with which no site demonstrated that it had engaged really effectively[41]. These groups include carers: of people with aggressive or unsociable behaviour; in areas of deprivation; who were bereaved / caring for people nearing end of life (NEOL); of people with HIV / Aids; of people with substance misuse problems; of people who were self-funding their care; and of people with mental ill-health; as well as male carers and working carers; (in some cases, only one site aimed to reach a specific group).

In the Devon site, work was carried out with young carers to design a health day at a local sports centre where health checks were delivered, and the site staff reported that this was well received. After it emerged that some carers in ethnic minority groups preferred having the option of checks delivered away from GP practices, health checks were also provided at other local community centres[42].

The NHS Support sites, together, achieved considerable success in reaching carers in some, though not all, of the groups they considered hard to reach or to include 'under-reached' carers. As can be seen from Table 4.4, successful approaches were used in engaging: carers in black and minority ethnic communities (three sites); carers of people with long-term conditions (one site); carers of people with dementia (two sites) or mental ill-health (three sites); and older, working and younger carers (each one site). More difficulty was experienced in engaging carers in some other groups. At least one NHS Support site tried to engage, but did not really evidence success in this with carers in the following groups: carers in areas of deprivation; bereaved / NEOL carers; Gypsy and Traveller carers; carers in areas of high health inequalities; carers of people with learning disabilities; male carers; and rurally isolated carers.

4.3   Identifying successful methods of engaging with carers

A range of approaches was adopted by sites to identify and engage with carers, including: working with healthcare professionals; working in partnership with a range of local authority departments; liaising with educational and youth organisations, community outreach work through voluntary sector organisations; marketing activities; and avoiding the term 'carer' in engagement and marketing activities.

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[41] In the evaluation of the DS programme, sites were not considered to have *demonstrated* effective working unless this was reported (or included in the information supplied) to the national evaluation team. There may have been achievements in some sites which were not disclosed in this way.

[42] The local evaluation report for the Devon site describes this approach as 'invaluable', reporting that of 72 health checks for ethnic minority people, 65 were delivered using this approach.

Engagement with carers through healthcare professionals

The main way NHS Support sites and many Health Checks sites identified and engaged with carers, particularly those considered 'under-reached', was by working with GP practices, hospitals or other healthcare professionals[43]. Several breaks sites also used this approach, which often involved extensive and ongoing work in the healthcare sector, including:

- Carer awareness and identification training for GPs and other healthcare professionals.

- Producing tailored marketing materials, including information displayed in GP practices and hospital wards, such as posters displayed behind hospital beds.

- Employing workers to identify carers directly in hospitals and GP practices.

- Using GPs' carer registers and referral systems.

- Using incentive payments to encourage GPs to refer carers to services (Health Checks and NHS Support sites only).

Four sites (including one from each type of site) attempted to engage with 'under-reached' carers through pharmacies, for example, by inserting cards or leaflets in prescription bags, or, in one case, encouraging pharmacists to identify carers directly.

The two NHS Support sites (Table 4.4) which supported the highest numbers of carers (Halton and St Helens, Hastings and Rother) both attempted to identify and engage carers in hospitals and GP practices through activities such as: raising awareness of carers and the issues they face; staff training; and using existing carer registers (see Box 4.1). This approach appeared to be relatively cost effective, as the total DS funding allocated to these two sites was relatively low compared with other NHS Support sites, as was cost per carer supported (see Chapter 6).

The techniques deployed in these two sites, however, required ongoing staff training and support and some staff (at these sites and elsewhere) questioned the long term sustainability of this approach. Engaging staff members already employed in healthcare settings (such as GP receptionists, practice managers, hospital staff) as 'carer champions' (to identify carers, provide information for carers and staff, and raise awareness of carers' issues) was proposed by staff in the South West Essex site as a more cost effective way of achieving similar results. Some staff at an NHS Support site (Hastings and Rother) suggested that an effective way to identify carers was through community based workers making home visits to sick or disabled people.

The survey of carers (the results of which are described in Chapter 5) showed that many carers had first heard about the support they accessed through healthcare professionals, suggesting this can be an important way of identifying and engaging with carers. In Health Checks sites, 42% of carers said they had found out about the DS services through their local doctor / GP, and staff in several sites reported that, despite challenges, working with GPs and health professionals had been an effective way to reach carers. The local evaluation report for the Halton and St Helens site reported that the most common way carers found out about services in hospitals was through direct identification in hospital wards, clinics and / or through professionals (44%). In the 12 Breaks sites, by contrast, the survey of carers showed far fewer carers there (9%) had found out about DS services through GPs.

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[43] This seems to have been quite successful. The majority of carers identified in the NHS Support sites were carers not previously known to the sites (Table 4.4).

Staff in six sites (in all three types of site) reported some difficulties and challenges in working with healthcare professionals, particularly in the early stages of the programme. These challenges included: GPs who were sometimes reluctant to engage with the DS activities; inaccuracies in lists of carers held on GP databases, which frequently needed updating; and health care professionals lacking time to prioritise identifying carers (as discussed in Chapter 3). Staff at three sites felt such problems led to (initially) lower numbers of carers supported than expected, although some were able to overcome these by adopting the techniques outlined in Box 4.1.

Box 4.1 Example of good practice: working with healthcare professionals to identify carers

The Halton and St Helens and Hastings and Rother NHS Support sites engaged with large numbers of carers by working with healthcare professionals to identify them. These sites both deployed specific techniques to encourage healthcare professionals to engage with the DS programme, after initial attempts were unsuccessful. Successful techniques used by these sites included:

- Ongoing awareness training on what a carer is and how to identify carers.

- Project support workers / liaison workers having a 'visible presence' in wards, hospitals, and GP practices to remind staff about referring carers.

- Giving feedback to GPs and hospital staff on outcomes for carers to demonstrate the benefits of the services, and to help build relationships of trust.

- Using techniques which save health professionals time, for instance: note pads on GPs' desks for quick and easy referrals; providing flexible training to fit in with health professionals' schedules; and providing concise information materials.

- Regular newsletters to keep GPs updated.

Source: case study interviews.

Engagement with carers through local authorities

Partnership working with local authorities also played an important role in the sites' ability to engage with carers. Ten Break sites, three Health Checks sites, and two NHS Support sites tried to engage with 'under-reached' carers by working in partnership with local authorities and social work teams. In some sites, teams of social workers or community workers were used to refer carers to, and to promote, the DS services, while other sites used local authority registers of housing benefit recipients to identify and contact carers and / or those being cared for. In the survey of carers, 20% of respondents said they had found out about Breaks services through social services (the second most frequently cited source), although this percentage was much lower in the Health Checks sites (9%). The local evaluation report for the Lewisham Breaks site reported that most carers found out about the support services through direct contact with a social worker.

Engagement with carers through educational and youth organisations

Some Demonstrator Sites also worked with educational and youth organisations to develop innovative targeted approaches (see Box 4.2). Seven sites (one Breaks site, three Health Checks sites and three NHS Support sites) targeted both young carers and young adult carers through extensive work with schools, colleges, universities, and youth centres. Staff in these sites felt this approach was highly

effective, and the sites which identified large numbers of young carers (Torbay, Breaks; and Camden, Health Checks) used such initiatives. Initial difficulties, such as a lack of knowledge of carers among school staff, were overcome by raising awareness and building relationships between the site and school staff.

Box 4.2 Example of good practice: identifying young carers through schools and colleges

The Camden Health Checks site engaged with a large number of young carers through their young carers project, which was delivered by Crossroads Care Camden. One of the approaches they used to engage with this carer group involved working with schools, colleges and youth centres in the local area. This included regular visits to these organisations, promotional and publicity work, and talking to staff and individual young carers. Raising the awareness of school staff, who sometimes had little prior knowledge of carer issues, was a key activity. This awareness raising enabled staff to recognise young carers, and understand any connections between issues at school and the young person's caring role. Getting engagement from schools was an initial challenge, and this approach required extensive work to build relationships. However, it was described as 'one of the most successful partnerships' for reaching this carer group.

Sources: case study interviews, site documents.

Community outreach work through voluntary sector organisations

Many sites (15/25) worked in partnership with voluntary sector organisations, and identifying and engaging carers was often one of their key roles. All except two sites (one Breaks site and one NHS Support site) also partnered with local carers' centres and these often had responsibility for identifying carers. Some sites decided not to use the existing carer databases held by carers' centres, however, as they wanted to focus their efforts on identifying and engaging with carers who were previously 'unknown'.

Sites which undertook outreach work did so in partnership with voluntary sector organisations in community locations and in health and social care settings, and staff described these activities as particularly important in identifying carers who would be unlikely to 'self-identify' by seeing a poster or leaflet. Some sites recruited carer volunteers to identify other carers in the local community (see Section 4.4).

Many sites (particularly those offering breaks) sought to identify 'under-reached' carers through outreach work in local communities, often using voluntary sector staff to undertake this work. A variety of approaches was used, including: door knocking; stalls displaying information and leaflets at markets; attending and providing displays at community shows or events; publicising the DS services in shops and supermarkets, including distributing leaflets there; and delivering leaflets through local residents' letterboxes. Some sites (particularly Breaks and Health Checks sites) adopted specific approaches to identify and engage ethnic minority carers, including: employing workers from local ethnic minority organisations to identify carers; working with community groups, faith groups and mosques; attending events and festivals targeted at ethnic minority communities; and using translated marketing materials.

Outreach work involving voluntary sector organisations was thought by DS staff to be especially important. They felt carers, particularly those in certain target groups (young carers, ethnic minority carers, or Gypsies and Travellers), often trusted voluntary sector organisations and responded to them better than they did to local authorities and other official agencies.

As discussed in Chapter 5, a large minority of respondents to the carers' survey (32%) found out about the Breaks services through carers' centres, although the percentage of carers who found out about Health Checks support in this way was lower (25%). Almost one fifth of carers found out about both the Breaks and the Health Checks services (19% and 18% respectively) through 'other' sources which included: mental health teams and support workers, local branches of voluntary organisations such as Age UK and Rethink, hospices, existing respite providers, support groups and carers' conferences. The survey findings are consistent with the views expressed by many staff in the sites who believed local voluntary sector organisations (including carers' centres) played an important role in identifying and engaging carers. Many staff in the Breaks sites and some of the local evaluation reports for these sites also stated that 'word of mouth' was a powerful way of reaching carers, again consistent with evidence from the survey of carers which showed that 12% of respondents had found out about breaks services through a friend or relative.

Marketing activities

Most sites also used a range of marketing strategies to raise awareness of the DS services, including: posters and leaflets; placing advertisements and stories in local magazines, newsletters, newspapers, local radio, and on television; promotional DVDs, stationery and other IT accessories. Around half of Breaks sites (7/12) and NHS Support sites (4/7) used websites to publicise services, although only two Health Checks sites chose this approach (as discussed in Chapter 5, only 1% of carers responding to the survey of carers said they had become aware of the DS support directly via the Internet). A small number of sites used social media, such as Facebook, MySpace, Twitter, and YouTube. One NHS Support site took the step of devising a 'carer award' for the 'young carer' and 'adult carer' of the year, to increase awareness and create publicity about the services.

The financial resources allocated to marketing of this type are discussed in Chapter 6 and each site's marketing costs are shown in Tables 6.2, 6.4 and 6.6. Marketing costs varied greatly between sites, but no clear relationship between expenditure on marketing and the number of carers who accessed support was evident, although it can be observed that those sites which were particularly successful in engaging with carers (Tables 4.2, 4.3, 4.4), such as the Bristol and Hertfordshire (Breaks), Devon (Health Checks), Halton and St Helens and Hastings and Rother (NHS Support) sites, spent relatively modest amounts on marketing.

Staff in the sites often reported that posters and leaflets had only limited use, especially as a way of targeting people who did not identify themselves as carers, and some local evaluation reports – for example, from the Suffolk Breaks site – reported similar evidence. The survey of carers showed that a fairly small minority of respondents had found out about the service through an advertisement (9% in Breaks Sites and 5% in Health Checks sites), suggesting these methods did work for some carers, but may not have been an especially effective use of resources.

Assessing the direct impact of this kind of marketing is not easy. Carers may find out about services through multiple sources, and it can often be difficult to isolate the effects of these. Evidence from a Breaks site showed that carers who were identified through 'word of mouth' or 'door knocking' in local communities had often seen posters advertising services, but face-to-face contact or recommendation from a friend was important in determining the legitimacy of services, and for gaining further information. Gaining the trust of carers through face-to-face methods was therefore important in successfully engaging with them.

Avoiding the term 'carer' in engagement and marketing activities

Irrespective of the different approaches chosen to market the DS services or to engage carers, there was a widespread view among staff in many sites that it was important to avoid the term 'carer' in marketing materials and when talking to carers, particularly when attempting to engage those considered 'under-

reached' or 'unknown'. In many sites, staff were encouraged to ask questions such as: 'do you look after someone?' or 'do you help someone out?' rather than 'are you a carer?' Some 'carer champions' and support workers found they needed to spend a great deal of time talking with people who were providing care or support to a relative or friend before they were ready to identify themselves as 'a carer'.

Sites which were more successful at identifying and engaging with large numbers of carers, and in meeting their planned targets, often used a combination of different techniques and strategies: adopting specific, tailored initiatives for targeting certain groups of carers (such as those from ethnic minority communities) and ensuring that, where appropriate, these efforts were on-going rather than one-off initiatives. The Devon Health Checks site, for example, exceeded its planned target for carers supported, and delivered large numbers of health checks and other related support, using a range of approaches to reach carers, including: outreach work to carers through voluntary sector organisations; promotional events; working with healthcare staff; using existing carer registers; promotional work through the local media; leaflets; websites; publicity in GP practices; and engaging carers in clinics. This site initially had difficulties encouraging healthcare providers to refer carers to the DS support, and as a result introduced training and awareness-raising activities, which were successful in overcoming some of these difficulties (Box 4.3). This site also avoided using the term 'carer' in its later publicity materials.

As discussed in Chapters 2 and 3, sites that were successful in engaging with carers often experienced challenges in responding quickly to increased demand for services and sometimes a sudden influx of carers following a successful carer engagement campaign led to a 'bottleneck' or 'backlog' of carers awaiting services, at some points meaning extra staff were needed to meet demand.

Box 4.3 Example of good practice in engaging carers

The Devon Health Checks site successfully met and exceeded targets for carer numbers, and delivered the highest number of health checks. A combination of various marketing techniques was used to identify carers, including: events, working with clinical staff and using existing registers, promotions in the local media, leaflets, website promotions, publicity in GP practices and specific clinics.

To overcome initial challenges in obtaining target numbers of referrals from healthcare providers, including GPs and pharmacies, additional methods were deployed including: more targeted public promotion (e.g. radio, local newspapers) in areas where provider delivery was low; offering extra support to providers which were struggling to deliver; utilising additional providers; and regularly sharing suggestions with providers for good practice in identifying carers. Efforts were made to avoid using the term 'carer' in later publicity materials.

Tailored methods were used to identify ethnic minority carers through working with the Hikmat BME Centre, which identified carers by drawing on detailed local knowledge of service users, running awareness sessions at the Centre and at the local mosque, and connecting with other local ethnic minority groups.

Sources: case study interviews, site documents.

4.4   Involving carers in service planning, delivery and evaluation

Sites were encouraged, through the DS prospectus (DH, 2009), to actively involve carers in the planning, delivery and evaluation of the support services offered. Nearly all sites set out plans, in their original bids, for carer involvement, although the approaches and extent to which carers were involved varied considerably. This section evaluates the levels and nature of carer involvement throughout the planning, delivery and evaluation of the DS programme.

Type and levels of carer involvement

All except one Breaks site (East Sussex) outlined some degree of carer involvement in their original bids, and methods ranged from involving carers in the project board, or in carer task groups, to using carers as evaluators of the services or trainers of carer volunteers. Plans for carer involvement were not always implemented, although some sites (Torbay, Breaks; and Camden, Health Checks) had comprehensive carer involvement plans which were implemented more or less as planned (Appendix C, Tables C.5, C.6 and C.7). Other Health Checks sites (such as Camden and Trafford), which initially had only limited plans for involving carers, adapted their plans during the delivery period to involve carers much more widely. The Redbridge site (Health Checks), in contrast, had difficulties implementing its planned range of carer involvement activities and as a result carers had a much more limited level of involvement in site activities than was originally intended.

All sites involved carers in planning delivery, either through the main site programme steering group or through task groups which were set up to deal with specific issues, such as marketing and communications or initiatives to target certain groups of carers. Many sites (16/25) also involved carers through a carers' forum, often run by the local carers' centre and designed to discuss services and policies for carers.

A number of sites (8/25) attempted to involve carers from the outset, engaging them in the initial development of the bid, and in the early stages of designing site materials and activities. This sometimes took place through carer consultation events or workshops held as, or just before, the site began service provision. Some sites hosted events for large numbers of carers and one used this approach as a way of gaining feedback from a representative range of carers. Carer feedback from these consultation events was often used in the initial design of the support offered: four sites involved carers in the design of health check questionnaires and documents; one site involved carers in the development of an NHS Trust Carers Charter; and another site involved carers in developing personalised breaks. In other sites, carers were involved in selecting evaluation tools or in developing strategies to address cultural barriers which might prevent carers engaging with the programme. An example of good practice relating to involving carers from the outset is provided in Box 4.4.

In some sites, carer input had only a limited influence on service design and planning. In case study interviews and quarterly calls, staff in several sites reported that carers had not been consulted or actively involved at an early enough stage. A carer representative's comment illustrated how this could occur:

> *When I came in, they'd already decided what they were going to do. So I came in and they just told me what they were doing. I would have liked to have been a bit more involved.*

In a few cases, staff had different perceptions of the extent to which carers had been involved, with some feeling there had been strong involvement while others described carer input as minimal.

> ### Box 4.4 Example of good practice: involving carers in designing site materials and activities
>
> The South West Essex NHS support site had a high level of carer involvement in design and planning (in addition to involvement in delivery) from the early stages of its project. This approach was described as beneficial by the staff and carer trainers interviewed. South West Essex included carers in the following ways:
>
> • In events/workshops before the start of the project, to determine what outcomes they would like from it.
>
> • In developing the project bid and tender.
>
> • In project steering groups, boards, and work-streams.
>
> • In delivery as carer evaluators, delivering awareness training, marketing the project, editing the newsletter, and moderating the website going forward.
>
> One member of staff said, *"Carers have been involved from the start. Their experience has been utilised and we've ensured that they've always been there questioning what we are doing, whether it's appropriate, whether it's beneficial in terms of cost as well. So, they have been there supporting us all the way."*

Source: case study interviews.

Nine sites (Derby, Suffolk and Torbay: Breaks; Camden and Trafford: Health Checks; Bolton, Halton and St Helens, Northamptonshire and South West Essex: NHS Support) involved carers directly in delivery, including: carrying out administrative work; supporting project workers in providing awareness training to professionals; running a carer-led social enterprise (including a café for carers with Internet access, training provision, and a property for carers' holidays [also rented out to non-carers]); supporting other carers as part of a befriending scheme; designing, developing and moderating a website; becoming health trainers (to support other carers); being involved in carer steering groups responsible for developing services and breaks; and becoming carer ambassadors (advocates for carers). Three of these sites were also successful in engaging with large numbers of carers and / or meeting their original targets (Halton and St Helens, Suffolk, South West Essex; see section 4.2 and Tables 4.2, 4.3 and 4.4) and the nature and level of carer involvement may have been one of the factors contributing to their success.

Carers were also involved in identifying and engaging other carers in the support services offered through the DS programme. This included: assisting at carer events / road shows; distributing leaflets; and visiting public spaces, hospitals and GP practices to identify carers. Some sites involved carers in developing publicity and marketing materials such as promotional DVDs or video clips, social networking pages, and newsletters, while others involved carers in interview panels for recruiting DS staff. Two Breaks sites also involved carers in a decision-making consortium / panel for the allocation of funds for carer breaks.

Alongside carer involvement in delivery of the DS service provision, sites also attempted to involve carers in the evaluation of their services. The level and nature of this involvement varied, with five sites involving carers as peer interviewers (including two Breaks sites, one Health Checks site, and two NHS Support sites). Three sites (one of each site type) involved carers in gathering quantitative survey and / or management information data. About half the sites involved carers in developing and / or reviewing evaluation and delivery materials. Some sites also gathered formative feedback during delivery of their

activities to inform ongoing design and delivery, using consultation events or surveys. Carers were consulted in the design of websites in five Breaks sites and in one NHS Support site.

Some sites successfully engaged carers in all stages of the process, including service design, delivery and evaluation. A particularly good example of this is outlined in Box 4.5. This approach, adopted by the Torbay Breaks site, was described as beneficial to the carers by site staff, as well as by carers interviewed by peer evaluators; positive comments of this type were also made in the interviews for both the local and national evaluation. As one carer volunteer leading on website development said, *'We have been supported and empowered by the PCT'.*

Box 4.5 Example of good practice: involvement of carers in design, delivery and evaluation

The Torbay Breaks site involved carers throughout the design, delivery and evaluation stages, as both paid employees and volunteers.

For programme planning, carers were represented in various task groups, on the project board, and on operational management team meetings.

Carers were involved in delivery through the design, development and moderation of a local carers' website, running groups and classes at the carers' centre, marketing, delivering awareness training, and assisting with various campaigns to publicise the project and reach 'unknown' carers.

Carers were involved in the local evaluation as 'carer evaluators', and contributed to the design of questionnaires, and conducted peer interviews with carers. The Torbay site gathered feedback from carers involved in the project, and from carers interviewed by carer evaluators.

Sources: case study interviews; quarterly calls; site documentation.

Benefits of involving carers

In many sites staff felt involving carers was worthwhile overall, sometimes highlighting this as one of the elements that had worked particularly well in the DS programme. One of the main benefits of involving carers in the design, delivery and evaluation of services was that services could be tailored more specifically to carers' needs. Many staff, in all types of sites, said carer involvement was beneficial and considered carers' 'expert' perspective was crucial in designing services which effectively met carers' needs. As one case study interviewee stated:

> *Everything we are doing is about carers, so carers should be at the centre of this. That is the logical place to start with everything, because we need to make sure what we are delivering with the services is what carers want and need, and that information materials are easily understandable to carers.*

A number of DS staff felt carers often offered an alternative perspective to that of social and healthcare professionals, raising issues professionals had not considered. In one NHS Support site, for example, carers pointed out that not all carers have Internet access and that alternative forms of communication are therefore important. Carers in one Health Checks site drew professionals' attention to some of the complex ways caring can affect health and well-being (such as emotional health, or dietary issues). Staff in Health Checks and NHS Support sites mentioned the effectiveness of using carers in awareness-raising training, as one project worker said:

...in training they're invaluable because you cannot beat somebody giving first-hand experience. So you can tell somebody's story but it doesn't have the same impact as somebody who says: 'This is what happened to me when I went to my GP.' If they say it themselves it's just the way it's delivered, it will have a much bigger impact on the audience.

An important benefit of involving carers in the work of the sites was the way it appeared to have an effect on the carers who became involved. In sites where carers were involved in design and delivery of the services, site staff and carer volunteers felt the involvement offered carers:

- Positive and enjoyable experiences.

- A feeling of being recognised and valued as 'experts'.

- Opportunities for skill development.

- Experience relevant to paid employment.

- Confidence-building opportunities.

- A way of combating isolation and developing new social / peer support networks.

- A chance to express their views to professionals.

- Empowerment.

- Useful and enjoyable training.

Some sites (Suffolk and Torbay: Breaks; Camden and Trafford: Health Checks; Northamptonshire: NHS Support) were planning to continue developing carer involvement, which staff in these sites described as a 'legacy' of the DS programme. Staff in several of these sites described setting up carers' support groups, forums or social enterprises which were designed to be sustained beyond the project, and continued independently by carers with support (where needed) from voluntary sector or statutory organisations (Northamptonshire, Torbay, Suffolk). The Torbay Breaks site, for example, was exploring options for ongoing funding to enable carers trained as carer evaluators to continue carrying out research for commissioners and the 'integrated health and social care' trust that led the DS partnership (further discussion of sustainability is provided in Chapter 6).

Challenges in carer involvement

Although carer involvement was generally viewed as positive, staff in many sites also identified challenges in involving carers in the design, delivery and evaluation of services, reporting that carer involvement was not always as effective as planned. Difficulties mentioned by staff included: the timeframe for the DS programme; boundaries between professional and caring roles; and the representativeness of the carer involvement.

Staff in several sites pointed to difficulties relating to time constraints in involving carers. In one Health Checks site, for example, some carers had requested papers for review six weeks in advance of meetings, which staff had found difficult to respond to. At a Breaks site, staff noted there had been insufficient time to accommodate carers' opinions in designing a website, resulting in limited carer input. Staff in another site said their arrangements for involving carers had started much later than planned because of practical difficulties – both staff changes and the time needed to identify and train carers. Similar delays were experienced in some other sites, including delays caused by CRB (Criminal Records Bureau) checks. Some staff felt the caring responsibilities of carers made it difficult for them to commit to the regular input needed for involvement in the programme, and there were some difficulties with carer 'attrition' on steering and advisory groups and low attendance at meetings. Attempts were made

to overcome these difficulties; for example, one site allowed carer evaluators flexibility to conduct peer interviews by phone, rather than face-to-face, if they were unable to leave the person they cared for.

There was some reticence among staff in Health Checks sites about carer involvement linked to concerns about professional boundaries. Some healthcare professionals were reported to have felt 'threatened' by the involvement of carers, believing carers were 'taking over' staff roles, or that carers lacked necessary knowledge / expertise. One clinical member of staff felt carers' views needed to be balanced with professional experience / expertise, commenting, *'sometimes carers are wrong'*. Some staff believed carers often lacked necessary experience or found it difficult to focus on DS issues. Elsewhere, however, staff emphasised the contribution made by carers' diverse backgrounds and skills to the implementation of the DS programme, noting that carers had brought skills in art, computing / web design, marketing and business systems. In a Breaks site, a staff member said, *'We get expertise that carers have, because carers are not just carers, they are other people as well.'* Another observed, *'We should celebrate and value caring and the wider skills and assets that carers have, rather than focusing solely on the negatives'.* Drawing attention to the fact that health and social care staff were sometimes carers themselves, one interviewee remarked that it was better, when planning carer involvement, not to think of carers as a 'separate' group of people. A few concerns were also raised about how representative those carers who became involved were of all carers, particularly as involving 'under-reached' groups of carers had proved difficult.

Key Findings

This chapter has evaluated the ways in which the Demonstrator Sites identified and engaged with carers, involving them in design, delivery and evaluation of the programme.

- Both the target numbers of carers and specific target groups of carers varied between sites, as did the extent to which these targets were achieved.

- Five sites met or exceeded their overall carer targets (Hertfordshire: Breaks; Redbridge: Health Checks; Hastings and Rother, Swindon, and West Kent: NHS Support), with five coming close (Bristol and Suffolk: Breaks; Devon: Health Checks; Halton and St Helens and South West Essex: NHS support). NHS support sites appeared to be more successful in this respect.

- Most sites identified several target groups in their bids, with the Health Checks sites targeting a particularly wide range of carers.

- The profile of carers supported by the sites was of predominantly older, female carers. However, sites were also successful in engaging carers from ethnic minority communities, particularly in the Breaks and Health Checks sites. Carers of people experiencing dementia, mental ill-health, long-term / terminal illness, learning disabilities and substance misuse problems were also well represented in the sites, when compared to the national profile of carers.

- Success at engaging with all carers and specifically target groups was determined, in part, by the types of engagement initiatives that sites selected. Although some sites faced challenges in engaging GPs and other healthcare professions, these partnerships were important ways of reaching carers, particularly in the NHS Support sites but also in some Health Check sites.

- Partnership working with youth and educational organisations also played an important role in sites' abilities to engage with carers. Innovative approaches to reaching young carers through partnerships with schools, colleges, youth centres and universities worked particularly well.

- Many sites worked with voluntary sector organisations (including carers' centres) to undertake outreach work, with Breaks sites most likely to use this method. These approaches seemed to be particularly effective in engaging with ethnic minority carers.

- Most sites developed a range of marketing strategies to raise awareness of the DS services, with websites used in some. Gaining the trust of carers through face-to-face methods was seen as a more effective way of engaging with them.

- There were no clear links between sites which spent a lot on marketing and those that engaged with large numbers of carers.

- There was a widespread view among staff in many sites that it was important to avoid the term 'carer' in marketing materials and when talking to carers, particularly when attempting to engage those previously unknown.

- Sites more successful at identifying and engaging with large numbers of carers, and in meeting their planned targets, often used a combination of different techniques and strategies: adopting tailored initiatives for targeting specific groups (such as carers from ethnic minority communities) and ensuring that, where appropriate, these efforts were on-going rather than one-off initiatives.

- All sites attempted to involve carers in designing services, and nine directly in delivery. Three sites (Halton and St Helens, South West Essex, Suffolk) which involved carers were successful in engaging with large numbers of carers and / or meeting their original targets, suggesting that the nature and level of carer involvement may have been one of the factors contributing to their success.

- Sites attempted to involve carers in the evaluation of their services, and again the level and nature of this involvement varied. Some sites successfully engaged carers in all stages of the process, including service design, delivery and evaluation.

- Involving carers in the design, delivery and evaluation of the sites was seen as one of the elements that had worked particularly well in the DS programme. It offered an alternative perspective to that of social and healthcare professionals, raising issues professionals had not considered and benefitting the carers who were involved in a number of ways.

- Some sites planned to continue developing carer involvement in service development, which staff described as a 'legacy' of the DS programme.

Chapter 5
Carers and their Experiences of the Demonstrator Sites

Sue Yeandle with Lisa Buckner and Viktoria Joynes

5.1   Introduction

As well as delivering support to a wider range of carers, exploring effective means of supporting carers and understanding how delivering support in new ways would affect roles and relationships in the health and social care system, the Demonstrator Sites programme also aimed to make a contribution to the evidence base on good practice in delivering carers' services. Sites were encouraged to explore and develop initiatives that would drive forward the aims of the 2008 National Carers' Strategy, with building a stronger evidence base on how outcomes for carers can be improved an important element of the DS programme. In all three types of site, services were delivered to carers with diverse characteristics and in a wide range of circumstances (target groups are discussed in Chapters 2 and 4), with staff in the sites committed to meeting carers' needs in a 'personalised' way (Chapter 3).

This chapter provides information about the carers who accessed support through the DS programme and their perceptions of the support they received. It finds that the sites were effective in reaching some carers - carers in ethnic minority groups, carers of people with some health conditions, and carers likely to need support in maintaining their own health and well-being - but that, overall, the carers supported through the DS programme tended to be rather older, and were much more likely to be women, than the total population of carers. The study also found that carers were strongly positive about the support received and that few had negative comments about or experiences of the programme.

The chapter is organised as follows. Section 5.2 describes the characteristics of carers who provided relevant information in Individual Carer Record (ICR) returns or in the survey of carers (see Chapter 1), and compares these with data from official large-scale data sets. Carers' experiences of the DS programme, as indicated in their survey responses (Carers Breaks and Health Checks sites only) are examined in section 5.3. This section explores how far the service received was a new form of support for them; how they became aware of the service they received and what they thought of it, and how they felt receiving the service had affected their health, caring situation and other aspects of their lives. Section 5.4 draws more widely on the study's evidence base, highlighting the perspectives of carers receiving support and of staff involved in providing the services, drawing on the case studies, staff interviews and surveys and documentary sources described in Chapter 1.

5.2   Characteristics of carers who took part in the Demonstrator Sites programme

Information about the personal characteristics of carers who engaged with the sites is available from the ICRs supplied to the national evaluation team by the 25 sites, as described in Chapter 1[44]. In total, 5,050 ICRs were submitted, representing 27% of the 18,653 carers who received DS services (Table 5.1). The results of the ICR analysis were compared with data on all carers in England (using the 2001

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[44] Some local evaluation reports also covered this topic, but necessarily did so in relation to only one site.

Table 5.1 Characteristics of carers who accessed support or services in the Demonstrator Sites   (%)

Demonstrator Site	Carers (ICRs)		Age				Gender		BME (all except White British)	Health poor (in last 12 months)	Of working age	In employment (carers of working age)	50+ hours p. w.	Caring for:	
	Number	% receiving DS services	18-24	25-49	50-64	65+	F	M						5+ years	2+ people
Carers Breaks sites	**2,061**	**36**	**3**	**27**	**37**	**32**	**69**	**31**	**14**	**33**	**68**	**28**	**74**	**54**	**14**
Bath & NE Somerset	240	42	1	26	35	38	74	26	30	23	62	40	74	65	13
Bristol	292	40	4	36	30	29	75	25	11	33	71	32	58	65	19
Derby	66	7	0	12	26	62	49	51	6	26	38	17	80	48	9
East Sussex	452	75	0	5	18	77	63	37	13	33	23	40	63	15	3
Hertfordshire	54	8	0	7	36	57	87	13	50	15	43	47	96	52	2
Lewisham	30	30	0	38	0	63	73	27	10	60	38	0	-	20	0
Liverpool	242	91	4	24	45	27	71	29	22	36	73	20	92	74	19
Nottinghamshire	73	10	2	24	22	53	64	36	22	32	47	25	76	49	11
Suffolk[1]	248	49	-	-	-	-	67	33	3	37	-	-	65	59	23
Sunderland	287	74	2	34	45	18	70	30	0	43	82	31	88	73	18
Torbay	74	29	18	13	34	35	68	32	0	21	65	28	58	44	18
Warwickshire[2]	3	12	-	-	-	-	-	-	-	-	-	-	-	-	-
Health Checks sites	**2,380**	**44**	**2**	**19**	**34**	**46**	**72**	**28**	**19**	**15**	**54**	**35**	**75**	**60**	**18**
Camden	192	72	12	36	34	18	77	23	53	26	82	27	69	62	15
Devon	1,158	40	0	14	36	50	71	29	2	16	50	46	70	57	7
Northumberland	457	100	0	8	30	62	69	31	0	15	38	26	81	57	4
Redbridge	310	52	0	30	50	20	74	26	55	12	80	38	86	70	16
Tower Hamlets	218	37	6	49	30	16	72	28	66	10	84	16	78	64	2
Trafford[1]	45	7	-	-	-	-	84	16	14	28	-	-	82	73	18
NHS Support sites	**609**	**8**	**1**	**22**	**43**	**34**	**69**	**31**	**10**	**31**	**66**	**42**	**59**	**45**	**14**
Bolton	123	16	1	22	43	34	69	31	12	25	66	36	62	57	16
Halton & St Helens[2]	18	1	-	-	-	-	-	-	-	-	-	-	-	-	-
Hastings & Rother[2]	36	3	-	-	-	-	-	-	-	-	-	-	-	-	-
Northamptonshire	52	9	0	24	39	36	62	38	8	44	63	48	76	52	12
South West Essex	63	14	0	30	51	19	77	23	2	14	81	44	47	52	17
Swindon	47	8	0	33	39	28	73	27	19	18	72	48	38	59	24
West Kent	270	47	2	20	38	40	68	32	12	40	60	32	57	37	12
ALL Demonstrator Sites	**5,050**	**27**	**2**	**22**	**36**	**40**	**70**	**30**	**16**	**24**	**60**	**33**	**73**	**56**	**13**

Source: ICRs. *Notes*: %s may not add to 100 due to rounding. Notes: [1.] Age data not available. [2.] %s not shown where: fewer than five ICRs were returned; fewer than 5 carers responded to the question; or the number of ICRs returned related to <5% of carers supported at the site.

Census[45] and the 2009/10 Survey of Carers in Households as benchmarks), and are presented in Tables 5.2 and 5.3[46].

Carers who accessed the DS services

The main characteristics of the carers for whom ICRs were available are shown in Table 5.1. In all three types of site, most were over 50 years old (with many over 65) and over two-thirds of all carers supported were women. In the Breaks sites 14% were from ethnic minority groups (comparable figures for the Health Checks sites and NHS Support sites were 19% and 10% respectively). Overall one in four (24%) carers reported poor health in the previous 12 months: 33% in the Breaks sites; 15% in the Health Checks sites; and 31% in the NHS Support sites[47]. In the NHS Support sites two thirds of carers were of working age (compared with 54% in the Health Checks and 68% in the Breaks sites). Among those of working age, over a third, across all sites (35%), were in paid work (28% in Breaks sites, 35% in Health Checks sites and 42% in NHS Support sites).

Comparison of the data in Table 5.1 with data for carers at the national level showed that carers accessing the DS services and support were considerably more likely than carers in general to be older, female, to have been caring for ten years or longer and to be caring for 50 or more hours per week. Carers in ethnic minority groups were also well represented (Tables 5.2 and 5.3). Observations based on these data include that:

- The tendency for carers to be older was particularly marked in the Health Checks sites (where 46% were aged 65+). As shown (Table 5.1), the Breaks and Better NHS Support sites had high proportions of carers aged 50-64 (37% and 43% respectively).

- Sites were quite successful in targeting their services to reach carers in many ethnic minority communities[48] (Chapters 2 and 4). In eight sites over 20% of carers described themselves as belonging to a group other than 'White British' (Table 5.1): Hertfordshire, Liverpool, Nottinghamshire: Breaks; Bath and NE Somerset, Camden, Redbridge, Tower Hamlets: Health Checks. All had 'reaching out' to carers in these groups as one of the site's targets or aims.

- The sites succeeded too in reaching many carers with substantial and long-term caring roles. The figures shown for the DS are considerably higher than those recorded in a recent, nationally representative survey of carers (Table 5.2).

- Sites were also successful in reaching carers of people with particular conditions: dementia, mental ill-health, long-term / terminal illness, a learning disability or substance misuse problems (as discussed in Chapter 4). The proportion of carers in these categories was higher than in the recent estimates for the overall population of carers in England (Table 5.3).

- The sites had some success in reaching carers combining work and care, a group often poorly represented among carers in touch with or receiving services (Yeandle et al., 2007c). Across all sites, a majority of carers were people of working age (60%) and of these a third (33%) were carers in paid employment. This figure was highest in the NHS Support sites (42%), with the figures in the Breaks and Health Checks sites 28% and 35% respectively) (Table 5.1).

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[45] A later Census took place in spring 2011, but data from it are not due to be released until 2012/13.
[46] Throughout this chapter, reference to the characteristics and circumstances of carers relates to those carers for whom ICR data was available, unless otherwise specified.
[47] Poor health in the past 12 months was reported by 8% of all non-carers of working age in England in the 2001 Census (Fry et al., 2011:48). Of carers who provided 50+ weekly hours of care, 17% reported poor health in the past year in the 2001 Census (Buckner and Yeandle, 2005). The DS thus seem to have been successful in accessing carers particularly likely to need health and well-being support.
[48] Data on the ethnic composition of local populations were checked to assess this.

• In total, 73% of carers were people caring for 50 or more hours per week (Table 5.1). This extremely high figure, notable across the DS, was highest in the Breaks sites (74%) and Health Checks sites (75%) and lowest (59%) in the NHS Support sites[49].

• Most carers (56%) who accessed services had been caring for five years or longer (Table 5.1). The NHS Support sites had more 'newer' carers (30% were carers who had been caring for less than two years) than the other types of site (the corresponding figures were 19% in Breaks sites and 16% in Health Checks sites; figures not included in tables). The higher figure in the NHS Support sites suggests these sites were having some success in their aim of promoting 'early identification' of carers.

Table 5.2   Carers who accessed the DS programme, compared with all carers in England, by gender, age and ethnicity[1]   **%**

		Carers accessing DS services	All carers in England (Census 2001)
Gender	n=4,990		*Carers aged 18+*
	Men	30	42
	Women	70	58
Age[2]	n=3,615		*Carers aged 18+*
	18-24	2	5
	25-34	4	10
	35-49	18	30
	50-64	36	36
	65-74	20	12
	75+	20	6
Ethnicity	n=4,907		*Carers aged 16+*
	White British	84	90
	White Irish	1	1
	Other White ethnic groups	2	2
	Mixed ethnic groups	1	1
	Indian	3	2
	Pakistani	1	1
	Bangladeshi	3	1
	Other Asian ethnic groups	1	0
	Black Caribbean	2	1
	Black African	1	1
	Other Black ethnic groups	0	0
	Chinese	0	0
	All other ethnic groups	1	0

Sources: ICRs; 2001 Census Standard and Commissioned Tables, Crown Copyright. *Notes:* [1] ICR data was available for 5,050 carers (27% of all carers who engaged with sites). [2] Age data relate to data supplied by 23/25 sites

[49] The 2001 Census showed 21% of all carers cared for 50+ hours per week. The Survey of Carers in Households 2009/10 estimated that 22% of all carers cared for 50+ hours per week.

Table 5.3   Carers who accessed the DS programme, compared with all carers in England, by duration and intensity of caring role   (%)

	Carers accessing DS services	All carers in England (Carers in Households)
Carers for whom data available		
Duration of caring role *n= 4,901*		
Less than 6 months	3	4
6 months but less than 5 years	41	*45*
5 years but less than 10 years	22	24
10 years or more	34	27
Hours of care per week *n=4,465*		
1-19 hours	9	52
20-49 hours	18	18
50+hours	73	22
Carers of *n=5,005*		
More than one person	13	17
A person with dementia	27	10
A person with mental ill health	30	13
A person with long-term or terminal illness	44	4[1]
A person with a learning disability	16	11
A person with substance misuse problems	3	1[2]

Sources: Demonstrator Sites: survey of carers, University of Leeds, Carers' Breaks wave 1 / Health Checks wave 1.
[1] Figure is for carers of a person with terminal illness, so not directly comparable.
[2] Figure is for carers of a person with alcohol or drug dependency, so not directly comparable.

Caring relationships of carers who accessed the DS services

Information about the relationships between the carers who accessed the Demonstrator Sites and those they cared for are presented in Table 5.4. Almost half the carers (48%) were caring for a spouse or partner and about a quarter (24%) for a parent. About 15% were caring for a son or daughter, this group split more or less evenly between those caring for a sick or disabled child aged under 20 and those caring for an adult son or daughter. Only a small number were caring for friends or for other relatives. A minority (8%) reported that they cared for people in more than one of these categories. Table 5.4 presents this data by site type and individual site, showing only a small degree of variation from the average figures across all sites.

The care needs of the person(s) cared for by carers accessing the Demonstrator Sites services were also recorded in their survey responses. Over 40% of carers said they were caring for someone with a physical disability, who was frail, or who had a long-term or terminal illness, and almost a third were supporting a person with mental ill-health or with dementia.

Having explored the characteristics and circumstances of the carers who accessed support in the Demonstrator Sites, the next section turns to their experiences of the programme, focusing primarily on the data available from the surveys of carers who received support in the Breaks and Health Checks sites.

Table 5.4 Carers who accessed the DS programme: relationship of person cared for to the carer   (%)

Demonstrator Site	Carers *number*	Spouse/ partner	Parent	Child (aged <20)	Adult child (aged 20+)	Other	Caring for 2+ people	ALL
Carers Breaks sites	**2,047**	**46**	**25**	**5**	**9**	**4**	**9**	**100**
Bath & NE Somerset	238	47	19	8	14	5	8	100
Bristol	292	35	22	13	8	7	13	100
Derby	66	*73*	*17*	*5*	*2*	*2*	*3*	*100*
East Sussex	448	63	29	0	0	6	2	100
Hertfordshire	54	63	26	4	4	2	2	100
Lewisham #	24	#	#	#	#	#	#	#
Liverpool	240	29	18	8	25	6	13	100
Nottinghamshire	73	56	25	1	3	6	8	100
Suffolk	248	40	33	1	6	4	15	100
Sunderland	287	43	19	5	14	5	14	100
Torbay	74	31	35	7	4	5	14	100
Warwickshire #	3	#	#	#	#	#	#	#
Health Checks sites	**2,354**	**51**	**20**	**8**	**8**	**6**	**7**	**100**
Camden	189	24	28	16	9	11	10	100
Devon	1,149	54	19	6	6	5	9	100
Northumberland	444	67	16	4	5	4	4	100
Redbridge	310	46	25	12	11	3	3	100
Tower Hamlets	217	30	21	11	12	14	6	100
Trafford #	45	#	#	#	#	#	#	#
NHS Support sites	**598**	**46**	**27**	**6**	**9**	**4**	**8**	**100**
Bolton	118	38	19	4	25	2	13	100
Halton & St Helens #	17	#	#	#	#	#	#	#
Hastings and Rother #	36	#	#	#	#	#	#	#
Northamptonshire	52	48	25	6	4	10	8	100
South West Essex	62	31	32	6	13	9	6	100
Swindon #	45	#	#	#	#	#	#	#
West Kent	268	53	27	6	4	1	7	100
ALL Demonstrator Sites	**4,999**	**48**	**24**	**7**	**8**	**5**	**8**	**100**

Source: ICRs.
Note: # %s not included due to small numbers. Data for these sites are included in overall totals for each type of site.

5.3   Carers' experiences of the Demonstrator Sites programme

As explained in Chapter 1, some carers accessing DS services were surveyed to gain an understanding of how they experienced and responded to the DS services. The survey also aimed to assess whether participating in the services and support changed their behaviour or improved their caring relationships. Section 5.3 presents data from those surveyed in the Breaks and Health Checks sites, who were asked questions about:

•   How they became aware of the DS service they accessed.

•   Whether they had received similar services or had relevant support before.

•   What they thought of the services they accessed.

•   How they felt their health, caring situation, and selected activities and behaviours had been affected by their engagement with the service.

They were also asked questions drawn from the WHO-5 standardised 'well-being' questionnaire, producing a 'before' and 'after' assessment of their well-being.

How carers accessed the service

The data from the survey shows that the most common way carers found out about the Breaks sites was through a carers' centre, and that the most common way they found out about the services available in the Health Checks sites was through a local doctor/GP (Table 5.5). As many of the partnerships formed to deliver the DS programme involved local carers' centres and GPs practices this was to be expected, although it does not necessarily mean these are the best ways to inform carers about these services.

'Reaching out' to carers who were not already in touch with services and support was expected of the sites in the DS programme (as discussed in Chapter 4). More than a quarter (27%) of carers responding to the survey found out about Breaks sites through the Internet, advertising or through 'other' means not listed in Table 5.7. In the Health Checks sites the corresponding figure was 24%.This suggests these are also effective ways of reaching some groups of carers. Further analysis (not shown in the tables) showed that very few 18-24 year olds (four out of 17 respondents) found out about Health Checks sites through GPs, hospitals, social services or carers' centres, and that most (13 out of 17) carers in this age group accessed these sites through other means[50]. By contrast, about three-quarters of carers aged 25+ found out about the sites through GPs, hospitals, social services or carers' centres.

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[50] Data are based on small numbers and not statistically significant
Sources: Demonstrator Sites: survey of carers, University of Leeds, Carers' Breaks wave 1 / Health Checks wave 1.

Table 5.5 How carers became aware of the Carers' Breaks and Health Checks services

	Carers' Breaks sites		Health Checks sites	
	Number of carers	%	Number of carers	%
Local doctor or GP	34	10	192	42
Hospital	9	3	8	2
Social services	72	20	24	5
Carers' centre	114	32	113	25
Internet	3	1	3	1
Advertisement	25	7	22	5
Friend/relative	44	12	17	4
Other	68	19	82	18
All respondents who answered the question	353	100	447	100

Sources: Demonstrator Sites: survey of carers, University of Leeds, Carers' Breaks wave 1 / Health Checks wave 1.

Carers' experiences and circumstances prior to accessing the services

Responses to two questions asked of carers who accessed the Breaks sites are shown in Tables 5.6 and Table 5.7. These show that, prior to accessing the new support, the overwhelming majority of these carers (80%) had not been able to take a break from their caring role, or had been able to do so 'only for a few hours' (Table 5.6). The majority (60%) also reported that it had been more than six months since they had last had a break from their regular caring routine, or said that they had never had such a break (Table 5.7). Taken together, the data in these tables suggest that the Breaks service was accessing carers very much in need of this type of support.

Table 5.6 Before accessing the Carers' Breaks service, were you ever able to take a break from your caring role?

	Number of carers	%
No	137	39
Yes, but only for a few hours	144	41
Yes, I can be away for a whole day if I wish	15	4
Yes, I can be away overnight if I wish	8	2
Yes, I can have a holiday or weekend break from time to time	44	13
All respondents who answered the question	348	100

Source: Demonstrator Sites: survey of carers, University of Leeds, Carers' Breaks wave 1.

Table 5.7 Before accessing the Carers' Breaks service, when, if ever, did you last have a break from your regular caring routine?

	Number of carers	%
Never	121	35
More than a year ago	56	16
Between 6 months and a year ago	32	9
Between 1 and 6 months ago	54	16
Within the last month (but not the last week)	35	10
Within the past week	46	13
All respondents who answered the question	344	100

Source: Demonstrator Sites: survey of carers, University of Leeds, Carers' Breaks wave 1.

Table 5.8 When was the last time you saw a healthcare professional about your own health? *(Excluding any attendance for a health check)*

	Number of carers	%
More than a year ago	61	14
Within the last year	47	11
Within the last six months	133	30
Within the last month	99	22
Within the last two weeks	105	24
All respondents who answered the question	445	100

Source: Demonstrator Sites: survey of carers, University of Leeds, Health Checks wave 1.

In the survey of carers who accessed the Health Checks services, respondents were asked when (not including any contact linked to the health check) they had last seen a healthcare professional about their own health. A large minority (46%) had done this in the previous month, and most had done so within the previous six months (76%). However a quarter of carers reported that they had not had such an appointment within the previous six months (Table 5.8). The Health Checks service thus attracted some carers who had not been in recent contact with health services prior to the check, but was in many cases providing additional healthcare support (possibly of a very different nature) to carers who, it can reasonably be assumed, also had access to other health treatments or advice.

Carers' views about the services they accessed

The carers responding to the survey who had accessed the Carers' Breaks services were mostly extremely positive about the support they had received, with 91% agreeing, or strongly agreeing, with the statement *'I would recommend this service to other carers'* (Table 5.9). There was also agreement (or strong agreement) with statements designed to explore if it had been easy to book a break (72%) or to contact someone to help find a break (71%) and if staff had been available to help them find the right break to suit their needs (72%).

Table 5.9 Carers' views about the Carer's Breaks Services they accessed   %

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	All responses (number)
Easy to find out about the service	17	43	23	14	3	333
Easy to book a break	26	46	19	8	1	302
Easy to contact someone to help me find a break	26	45	21	8	1	300
Staff were able to help me find the right break to suit my needs	28	44	22	5	2	294
I would recommend this service to other carers	63	30	5	0	4	316

Source: Demonstrator Sites: survey of carers, University of Leeds, Carers' Breaks wave 1.

Some carers wrote positive comments in the questionnaires they returned:

> *Just to think someone is listening to carers really helps. You do sometimes feel really alone, and that no-one cares.*

> *It has helped me feel valued as a carer. I feel carers are like an invisible army, often doing care work for family 24 hours a day, seven days a week, 365 days a year, year after year. We deserve recognition and financial help; the scheme has also boosted my self-confidence and mental and physical well-being.*

Others pointed to some of the difficulties they had experienced, noting that taking a break from caring did not necessarily relieve their worries as a carer:

> *I worry that: he's ok, he's not causing trouble, doesn't get confused and do something that hurts anyone, either emotionally or physically, or insults anyone. I spring on the phone in case it's the alternative care provider needing me.*

> *Providing substitute care is by far the most difficult aspect of taking a break. My mother does not want anyone else with her. It took a great deal of organising to provide her with company she would accept.*

A similar picture is seen in Table 5.10, which presents data from the Health Checks survey, and shows carers' views shortly after accessing a health check. Again, most carers were very positive about the accessibility of the service and the arrangements for making the check. Some carers indicated their positive responses in the questionnaires they returned:

> *I think this is an excellent service as it checks on the carer who often does not check their own problems.*

> *Valued support given to me as a carer, as usually the focus is on the person being cared for. Information given was helpful.*

Table 5.10 Carers' views about the Health Checks services they accessed
(shortly after HC)   **%**

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	All responses (number)
Easy to find out about the service	25	43	20	10	2	427
Easy to book a health check	39	52	7	1	1	425
Easy to contact someone to help me find a health check in my area	25	44	22	7	3	405
Information and the health check was easy to understand	40	53	5	1	..	437
I think this service is a good way to support carers	62	33	4	…	1	445
I would recommend this service to other carers	64	31	3	1	1	442

Source: Demonstrator Sites: survey of carers, University of Leeds, Health Checks wave 1.

The vast majority (95%) felt this was a good way to support carers and said they would recommend the service to other carers. However some did express surprise or disappointment about the health checks service they received:

> It would have been nice to have a doctor as part of the check-up to give a feeling of really looking into my health problems. I get embarrassed to have to keep going back to the doctor, so often neglect myself.

> I thought this would be a full health check - i.e. blood pressure, etc. – bloods.

> I was very disappointed with the health check. It was just filling in a form. A health check sounds like there are going to be some physical checks. This was not the case.

Most carers' views about the Health Checks service remained very positive four months later, when they responded to a follow-up questionnaire: 85% said they felt the staff involved had understood their caring situation; 96% said the check was conducted in a pleasant manner; and 93% said the venue for the check was easy to access (Table 5.11). Over two-thirds (68%) said that the health check was tailored to their needs, and 88% (compared with 95% in the Wave 1 questionnaire) said they would recommend the service to other carers.

**Table 5.11 Carers' views about the Health Checks services
they accessed, four months later**   **%**

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	All responses (number)
The service/staff understood my caring situation	45	43	9	2	1	233
The Health Check was:						
Tailored to my needs	15	53	24	5	3	229
Conducted in a pleasant manner	48	48	3	1	..	233
Easy to access (venue)	44	49	6	1	..	229
I would recommend this service to other carers	50	38	8	2	3	232

Source: Demonstrator Sites: survey of carers, University of Leeds, Health Checks wave 2.

Impact on carers' health, caring situation and activities

Analysis of data provided by 152 respondents to the Breaks Wave 2 questionnaire indicated that one third of respondents had received a 'well-being support' service from the Breaks site they had accessed. About one in six of these respondents had been allocated funding to enable them to take a holiday (weekend break or longer). Other carers (in smaller numbers) had accessed 'alternative care in the home' (usually as regular support), 'specialised short-term respite' (both as one-off and regular support) and 'training for other skills' (i.e. not work-related or caring skills). About one in five respondents said, four months after initially accessing the service, that they had not received a break. These carers variously reported that a break was not appropriate or needed, planned but not yet taken, or seemed confused about what a carers' break actually was, or could be.

The impact the Carers' Breaks services had on the survey respondents as individuals, both in terms of their caring situation and in terms of their own lives and behaviour, is presented in Table 5.12. This shows that almost half of carers felt that accessing the service had enabled them to have more time for themselves, build confidence, and improve the balance between their caring and other parts of their lives. Fewer carers said there was a change in how they acted or behaved, although more than one third had started a new leisure activity. About one in ten had applied for training or had begun volunteering and (of the small numbers for whom this was applicable), small but notable minorities had negotiated more flexible working arrangements or applied for a job. It is evident from Table 5.12 that access to a carers' break is not a panacea for carers, and of course after the break or breaks service, most still had very demanding caring roles to manage. It should also be borne in mind, however, that for many carers, caring often becomes more difficult and demanding over time as the health of the person they care for may deteriorate. Interventions designed to support carers while they are caring are therefore unlikely to have dramatic effects, and the results here indicate good outcomes in this context.

Carers' perceptions of how their health and well-being was affected by having access to the breaks services are presented in Table 5.13. This shows quite positive outcomes with regard to health, with large minorities saying that how they take care of themselves, look after themselves and feel about life

Table 5.12 Change in carers' situation / behaviour since accessing the Carers' Breaks service

	Yes %	No change %	No %	All responses (number)
I have more time for myself	46	32	22	134
The balance between my caring and other relationships has improved	49	29	22	133
My social life Is better	36	36	28	135
I have joined a new club or social group	20	26	53	133
I have started a new hobby or leisure activity	37	21	42	134
I feel more confident about my ability to take on new challenges	46	28	27	134
I have applied for a new training course	9	19	70	135
I have begun a new training course	9	17	73	134
I have applied to/become a student in FE/HE	5	19	76	133
I have started volunteering	10	25	65	133
I am considering returning to paid work*	8	40	53	40
I have applied for a new job*	8	22	70	37
I have started a new paid job*	3	25	73	40
I have negotiated a flexible working arrangement with my employer or reduced the hours I work*	11	24	65	37
I have increased the number of hours I work*	3	33	64	39

Source: Demonstrator Sites: survey of carers, University of Leeds, Carers' Breaks wave 2.
*Carers who responded that this question was 'not applicable' have been excluded from this analysis

had improved. The picture in relation to healthy behaviour, such as ability to relax, deal with stress and take regular exercise, is also broadly positive, with most carers recording improvements or no change. Separate analysis (not shown in the tables presented) which compared carers in the Breaks Wave 2 survey who said they had not received a break with all other respondents completing the four-month follow-up questionnaire, showed that carers who had *not* received a break were more likely than those who had done so to show a significant deterioration in their well-being scores (39%, compared with 29% for carers who received a one-off break and 24% for carers who received ongoing support, respite or well-being services).

There is also strong evidence that engaging with the service had improved some carers' communications and relationships with professionals, and that their knowledge of carers' rights and entitlements was significantly better after the support they had received in the Breaks sites. Results were also broadly positive on the measures about the quality of the care given to the person cared for, and the quality of life of the person cared for. Only a minority of carers reported improvements on these items in the questionnaire, but in every case there were far more carers saying the item had improved than that it had deteriorated.

Table 5.13 Impact of accessing the Carers' Breaks service on carers' health

Since accessing the CB service:	Has improved %	Has not changed %	Has got worse %	All responses (number)
The way I look after my own health	39	58	4	134
My general health	29	62	9	134
The way I take care of myself	40	54	6	136
How I feel about life	44	53	4	131
My diet	21	74	5	134
The way I deal with stress	42	52	7	134
My ability to cope	48	46	7	132
Taking regular exercise	38	57	5	133
My ability to relax	36	55	9	135
The care I give	39	59	2	132
My understanding of carers' rights / entitlements	43	56	1	126
My knowledge of how to access support / breaks	55	45	1	132
My communication with professionals and service providers	34	62	4	132
The support I get from professionals and service providers	30	64	6	130
The breaks or respite I get	42	55	3	130
My understanding of how to access local information and support	45	52	3	131
The quality of life of the person I care for	30	64	6	135
My ability to take care of the person(s) I care for	42	57	2	135
My relationship with the person(s) I care for	39	58	3	136
The standard of care I give	29	70	2	136
The independence of the person(s) I care for	19	71	10	134
The dignity and respect with which the person(s) I care for is (are) treated	23	76	2	133
The choices those I care for have about their care	11	86	2	132

Source: Demonstrator Sites: survey of carers, University of Leeds, Carers' Breaks wave 2.

The responses of carers who had attended a heath check or related service are presented in Table 5.14. Most carers felt that all of the items listed had been covered in the check, apart from 'safety in being a carer' which, perhaps surprisingly, only a minority (46%) of carers who responded to the questionnaire felt had been included. As with the carers who had accessed breaks, it was the impact on the behavioural aspects of their health that was most evident. Four months after the check about a quarter of respondents felt the way they looked after themselves, took care of their health, and the exercise they took had improved.

Perceptions of the usefulness of the support received were also generally positive. Most carers (56%) felt that they had been signposted to additional services or support in a way which was useful, but of the remaining 44%, 17% said they had been signposted to services which were of 'little or no use', suggesting that not all referrals were well thought through, or that some services to which carers were referred may not have been suitable for them (many carers did not require additional appointments, treatments or tests).

Table 5.14 Carers who accessed a Health Check: perceptions four months later   %

Topics covered in the health check	Yes	No	Don't know	All (number)
Physical health	94	4	2	228
Stress and emotions	77	18	6	231
Mental health	65	24	10	223
General wellbeing	92	6	1	232
Safety in being a carer (e.g. lifting and handling)	46	45	9	221
Lifestyle (e.g. diet, smoking, drinking)	80	16	4	228
Impact on the health check on carer's health	Has improved	Has not changed	Has got worse	All (number)
The way I look after my own health	28	67	4	227
My general health	13	75	13	229
The way I take care of myself	25	70	6	228
How I feel about life	13	76	11	230
My diet	19	77	4	231
The way I deal with stress	17	75	8	229
My ability to cope	21	70	9	230
Taking regular exercise	23	66	12	231

**Table 5.14 Carers who accessed a Health Check:
perceptions four months later (continued)   %**

Perceptions of support received:	Yes, it was very useful	Yes, it was of some use	Yes, but it was of little or no use	Did not receive this type of support	All responses (number)
I was signposted to additional services or support	18	38	17	27	208
I received advice on how to manage my health	19	42	11	28	217
I was helped to construct a health plan	8	19	6	68	210
I was offered a follow-up appointment	11	13	2	73	209
I was prescribed new medication/ treatments	5	4	1	89	201
I was referred to another medical practitioner	9	7	2	82	204

Source: Demonstrator Sites: survey of carers, University of Leeds, Health Checks wave 2.

Impact on carer well-being

Responses in the carer survey to the WHO-5[51] questions included within it made it possible to explore carers' well-being using a standardised measure, both before and after they had support in two types of site: Breaks and Health Checks. This is presented in Table 5.15. Data in the table are included only for those carers who responded to both waves of the relevant questionnaire (figures shown in the bottom row of the table). In both types of site, the proportion of carers who showed 'poor well-being', as measured by these questions, was higher after than before the service was received: this was particularly marked for those in the Breaks sites. This should not be read as a proven outcome of the service received, however (as a control group of carers who had not received the relevant service would be required to assess this)[52]. The time gap (approximately four months) is long enough for the caring circumstances of these carers to have undergone some change (which is likely to have made their caring role more difficult, as the situation of most sick or disabled people deteriorates rather than improves) over time[53]. There is evidence for this from the Carers' Breaks survey, which showed that carers whose well-being was significantly worse after they had been supported through the DS programme were more likely than other similar carers to be caring for someone whose health had deteriorated. As shown in Table 5.15, one third (32%) of carers in the Breaks sites, but only 14% of those in the Health Checks sites showed an improvement in well-being scores over the four months since first accessing support. Correspondingly, fewer carers (28%) in the Breaks sites showed deterioration in well-being scores than in the Health Checks sites (35%).

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[51] The WHO-5 measures psychological well-being using five items covering positive mood (good spirits, relaxation), vitality (being active and waking up fresh and rested), and general interests (being interested in things).
[52] This was not possible in the study, given the timescale, complexity of the DS programme and other factors.
[53] Especially those cared for by carers in this study, who often provided long hours of care.

Table 5.15 Well-being of carers in Carers' Breaks / Health Checks sites: before / after accessing the Demonstrator Sites service   %

	Carers' Breaks		Health Checks	
	At start of support	Four months after service	At start of support	Four months after service
WHO-5 Poor well-being	56	67	79	82
Change in WHO-5 wellbeing score				
Significant increase from start	..	32	..	14
No change from start	..	40	..	51
Significant decrease from start	..	28	..	35
Age of respondents				
18-49	12	13	20	21
50-64	41	40	33	37
65+	47	47	47	42
Gender				
Male	28	29	28	28
Female	72	71	72	72
Number of responses	221	221	172	172

Sources: Demonstrator Sites: survey of carers, University of Leeds, Carers' Breaks / Health Checks, waves 1 and 2.

Carers' experiences in the NHS support sites

Carers in the NHS Support sites were not surveyed in the same way as those in the Breaks and Health Checks sites (see Chapter 1). This was mainly because of the circumstances in which many carers accessed NHS support, often involving an acute episode, unexpected crisis or new diagnosis affecting the person they cared for[54]. Some carers in the NHS Support sites nevertheless conveyed their views about the service to the evaluation team. Their comments were overwhelmingly positive, although some revealed considerable past strain in their caring circumstances:

> *I feel that carers are being given the understanding and respect that they deserve in their difficult caring role.*

> *Hopefully, at last, carers are finally being recognised for the hard job they do.*

> *As I have been a carer for many, many years, my answers may not appear to be particularly positive. However, as a result of services received, my aims / attitudes have been reinforced and I have been able to use my knowledge etc. to help and support other (newer) carers.*

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[54] As explained in Appendix A, a questionnaire was distributed to some carers in NHS Support sites, at the request of staff in the sites, but yielded insufficient results for statistical analysis.

A few reported that the support had had unexpected positive consequences:

> *I have a better relationship with my own children and their families.*

> *Learning all the skills to cope has helped me with confidence and my outlook on the situation. I have now started up a new successful business because of all that has happened.*

5.4   Summary of benefits: staff and carer perceptions

During case study interviews staff were asked what they felt the main benefits of the DS programme were for carers and if they felt carers engaging with the DS services experienced benefits which were different from those they would get in other carers' services. The main emphasis of their answers was that:

- For many of the carers their contact with the DS was the first they had had with any services for carers. Staff felt these carers now felt 'reassured' that they knew 'where to turn to' if they ever needed support, even if they did not need immediate help.

- Offering services or access to services through carers' centres (rather than through social services or NHS provision) had made services accessible to carers who disliked or were reluctant to contact 'official' agencies.

- Carers receiving the DS services had become much more aware of services available.

Staff in the Breaks sites emphasised that breaks allowed carers to have time for themselves (Table 5.16), a point relevant to all similar services. Asked what was new or different about the support offered in the DS programme, staff often mentioned the flexibility of the services, which they felt had not been a feature of previous breaks services. Some said the breaks service provided within the DS programme was not significantly different from that offered previously, however, sometimes emphasising that they had 'built upon' previous provision.

Flexibility was particularly highlighted (in applicable cases) with regard to:

- The varied types of breaks carers could choose or identify for themselves.

- The more flexible eligibility criteria applied (DS services were not restricted to those eligible through a community care assessment of 'critical' or 'substantial' need).

- The ability to book a break online at any time.

Some staff noted that carers might not recognise some options available as 'a break'[55]. A summary of staff and carers' views about what was a new or different benefit of each type of Breaks service is presented in Table 5.16.

In the Health Checks sites, many staff noted that the main benefit to carers was the diagnosis of (previously undiagnosed) conditions. They also noted that:

- Offering a health check in carers' homes was beneficial (staff often noted that they often provided other services to people in their own homes).

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[55] Several carers in Breaks sites raised questions about what 'a break' from caring was, making comments such as: *'Needs to be re-named'* or suggesting that they had not received a 'break' (when, by the definition of a break used in the relevant site, they had): *'I got a greenhouse from the carers' centre… It has helped me at a lot, but I don't know anything about breaks - I wouldn't leave my husband with anyone. I would rather be with him 24/7 and my son.' 'I'm not aware of a Breaks Service, although I received a £100 grant whereby I left (cared for person) with a relative to allow a day break with my husband and children about 3 months ago.' 'It perhaps needs to be renamed or explained, as many people think it means going away on holiday.'*

Table 5.16 'New' benefits identified by staff / carers in Carers' Breaks Sites

Carers Breaks services by type	Staff comments / observations	Carers' perceptions
(A) Specialised short-term respite for carers of people with dementia / mental ill health	• Engaging people with dementia in activities in the community is an important alternative to traditional day-care, which is more rewarding for the carer / person cared for. • Taking time to build relationships of trust with both the carer and the person with dementia is important.	• Gives greater peace of mind to leave the person cared for, knowing they are being well looked after. • Those cared for are sometimes reluctant to attend respite care / be without their carer.
(B) Alternative care in the home	• DS services offer choice and control regarding when a period of alternative care is booked, and who it is delivered by, in contrast to most previous services. • Alternative care enables carers to have time for themselves and a 'life of their own'.	• Improves the ability to take a break, and / or have time for themselves. • Enables some carers to attend courses to improve career development. • It can be difficult for the person cared for to accept alternative care.
(C) Carers' holiday breaks: funding or facilitation	• A break does not always mean time away from the person cared for, and a holiday break can be important for carers / those cared for, enabling them to spend 'quality time' together.	• Provides a 'refreshing' break away from the caring role / cared for person – but it can be difficult to leave the person cared for. • Can provide quality time with the family and / or the person cared for. • Makes an otherwise unaffordable holiday break possible. • Reduces isolation.
(D) Practical help in everyday life	• A priority for some carers, rather than a break from caring. • Makes carers' lives easier and reduces stress.	• Support to maintain / improve the home environment has a positive impact and reduces stress / anxiety*.
(E) Well-being support/ services	• Reduce stress. • Give carers a chance to relax. • Help carers make positive life-style changes to improve health / well-being (e.g. give up smoking, lose weight) • Build confidence.	• Therapies and gym memberships improve fitness / well-being. • Promote relaxation / reduce stress. • Facilitate weight loss. • Increase confidence / self-esteem. • Offer an enjoyable experience.

Table 5.16 'New' benefits identified by staff / carers in Carers' Breaks Sites (continued)

Carers Breaks services by type	Staff comments / observations	Carers' perceptions
(F) Training for the caring role	• Enable carers to feel supported in their role. • Improve carers' ability to look after the person they care for.	• Opportunities to access training / activities in the company of other carers are valued (based on limited data)
(G) Work-related training	• Helps carers build skills and access opportunities for education / employment.	• Opportunity to learn skills (e.g. computing) is welcome. • Enables carers to attend courses to assist career development.
(H) Training for other skills	• Enables carers to build 'a life outside of caring', and develop other hobbies, interests and skills. • Facilitates social interactions / builds social networks.	• Courses can be enjoyable; relaxing; 'energizing'. • The chance to learn something new can be enjoyable. • Help in developing hobbies and interests outside of caring is appreciated. This offers carers an opportunity to socialise.
(I) Equipment and domestic goods funding	• Enables carers to choose a break that meets their individual needs. • Challenges traditional definitions of a 'break'. • Can be a relatively cost effective way to provide carers with a break which meets their needs.	• Can make new hobbies / leisure activities possible. • Computers can be used for leisure, practical activities (e.g. shopping) and social networking with distant friends / family. • Flexible breaks and choice of activities is appreciated. • Some confusion can arise over the terminology 'break' (to refer to equipment / domestic goods funding).
(J) Improving access to breaks	• Online booking systems can offer greater flexibility, choice and control over when and where alternative care is booked. • Benefits carers who do not want to access a break through social services / Carer's Assessment.	• Flexible access including booking through online systems valued*. • Greater flexibility in service provision still needed. • Disappointment results if / when breaks applications are turned down.

Sources: case study interviews, ICRs, local evaluation reports, site documents, QRTs, quarterly calls. Notes: # Data not supplied by site; * Insufficient evidence available.
[1] Based on data from the local evaluation reports and ICRs.

- Access to alternative care to enable carers to attend their own medical appointments was beneficial, as missing these was problematic for the carer and for the health service.

- Delivering health and / or wellbeing checks through, or with the involvement of, voluntary sector staff was a unique feature of the service offered[56].

A summary of staff and carers' views about what was new or different about each type of Health Checks service is presented in Table 5.17.

In the NHS Support sites, staff identified several new or distinctive benefits of the DS services for carers.

- The new links with, and carer awareness training for, GPs had led to the identification of carers who had previously 'slipped through the net'.

- Identification of carers in hospitals had led to an improvement in multi-agency working, with more carers being referred to ongoing support.

- The DS funding had enabled posts to be created through which dedicated staff worked as GP links, or as hospital-based carer support workers (previously, where improving support for carers had been tried, it had been done with scant resources and staff unable to meet the volume or geographical spread of demand).

A summary of staff and carers' views about what was new or different about each type of NHS Support service is presented in Table 5.18.

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[56] One member of staff suggested this was beneficial to carers because they would be willing to 'take up the time' of such staff with 'minor' concerns which they might feel they should not 'bother' a GP with – a point which needs to be considered in the context of the feedback from some carers, who said they would have preferred to see a GP or nurse (see section 5.3).

Table 5.17 'New' benefits identified by staff / carers in Health Checks Sites

Approach to Health Checks provision	Staff comments / observations	Carers' perceptions
(A) Physical health examination	• Carers often neglect their own health, and a physical health check helps them focus on their own health needs. • Other physical health checks (provided by GPs / other services) do not focus specifically on carers, or examine health in the context of the caring role. • Enables early identification and treatment of health conditions carers are unaware of.	• Attention to their own health needs, not just those of the person cared for, is welcome. • 50 carers in the Health Checks Wave 2 survey described previously undiagnosed health conditions identified through the checks. • Provided 'peace of mind', particularly when carers had experienced health problems in the past. • Some wanted additional physical tests not covered by the check.
(B) Well-being check	• A holistic approach to health and well-being is a new element in carer services. • Enables the causes (rather than symptoms) of health problems to be treated (e.g. stress caused by lack of support / need for a break from the caring role). • These frequently uncover emotional and mental health issues.	• Attention to well-being and emotional health in checks, as well as physical health, was valued, as carers realise the caring has an effect on emotional health. • Some carers felt the balance between emotional / physical health elements was not yet right, and wanted more attention to either emotional or physical health.
(C) Improving access to health checks	• Important to offer carers a choice of venue. • Most carers prefer to have checks in their own home (for convenience); some prefer a check away from the person cared for (for privacy). • Alternative care enables carers to attend appointments and receive treatment for serious medical conditions.	• The opportunity to have the check at a convenient time and place was valued, including the offer of a check in the home. • *93% of carers described the health checks venue as easy to access[1].* • Health checks were described as different from other health services, because of the 'quality time' spent with /listening to the carer.

Sources: case studies, interviews, Demonstrator Sites: survey of carers, University of Leeds (qualitative data).
Note: [1]Italicised text indicates statistical data from the survey of carers.

Table 5.18 'New' benefits identified by staff / carers in NHS Support Sites

Approach to NHS Support provision	Staff comments / observations	Carers' perceptions
(A) Hospital based carer support	• Healthcare professionals generally focus on the patient; carers' needs are often neglected. • Enables carers to be identified and supported early on; important for carers new to caring after a 'crisis'. • Can help carers to cope and prepare for hospital discharge. • A 'dedicated team of carer support workers' is important. • Improves recognition of carers as 'expert partners'.	• Provided better knowledge of available services; improved support and recognition. • Feeling there is 'someone to turn to' and a point of contact is valued. • Better able to 'cope / avoid breakdown' with this support.* • Can assist preparation for the hospital discharge of the person cared for.
(B) Primary Care based carer support	• Makes GPs and practice staff more aware of carers, and able to identify / signpost them. • Enables 'hidden' carer identification. • Increases referrals to further support. • Makes access to carers' services and support in GP practices possible.	• Support and awareness in GP practices improves access to appointments (not experienced by all carers). • Better able to cope in caring role as a result of support.*
(C) Befriending and peer support	• Supports carers to have a 'life of their own'. • Helps carers to access leisure and employment. • Reduces social isolation. • Contributes to personalisation.	• Positive experiences of 'carer cafes'/ coffee mornings: less isolated, meeting other carers, accessing information.
(D) Carer awareness training NHS staff	• Led to increased referrals and improved support for carers.	• Health care professionals are more aware of carers and recognise / understand them. • One carer felt increased awareness needed to be backed up by knowledge and time to help carers.
(E) Information about and for carers	• Enabled carers to access the right information at the right time. • Made carers more aware of available services and support.	• Aids understanding of the condition of the person cared for; helps carers feel less alone; enables them to look after their own health; provides access to practical support, benefits and services. • Some carers had *'discovered things they never knew about'*. One said: *'I didn't know there was so much support'*.
(F) Carer Assessments: delivery and/or documentation	• Improved the assessment process. • Co-ordinated assessment across local authorities (using common forms / protocols).	• Made Carers' Assessments more accessible.

Sources: case studies, interviews, Demonstrator Sites: survey of carers, University of Leeds (qualitative data).
*Also supported by local evaluation data.

Key Findings

This chapter has provided information about the carers who accessed support through the DS programme and their perceptions of the support they received. It finds that the sites were particularly effective in reaching some carers - carers in ethnic minority groups, carers of people with some health conditions, and carers likely to need support in maintaining their own health and well-being - although overall the carers supported through the DS programme tended to be rather older and were much more likely to be women than the general population of carers.

- Sites reached many carers with substantial and long-term caring roles and many were successful in targeting carers of people with dementia, mental ill-health, long-term / terminal illness, a learning disability or substance misuse problems.

- While carers tended to find out about the Breaks sites through carers' centres and about the Health Checks sites through their GP, a minority became aware of the services through advertising, friends / relatives or the Internet.

- In the Breaks sites 80% of carers had previously been unable to take a break from caring for more than a few hours; however 76% of carers who accessed health checks had seen a healthcare professional about their own health in the past six months.

- Carers were strongly positive about the support received and made very few negative comments about the programme. In both the Breaks and Health Checks sites over 90% said they would recommend the service to other carers.

- Accessing the Breaks services enabled half of carers to have more time for themselves and build confidence, although fewer reported changes in behaviour. A third started a new leisure activity, and large minorities said they subsequently took more care of themselves and felt better about life. Engaging with the service improved some carers' communications with professionals and knowledge of carers' entitlements. Carers who did *not* receive a break were more likely to show deterioration in well-being scores.

- Most carers who attended a heath check were satisfied with the service although 45% said 'safety in being a carer' was not covered. Four months later a quarter said how they looked after themselves and their health and exercised had improved. Most (56%) had been signposted to additional services, although a minority (17%) said these had been of 'little or no use'.

- In both Breaks and Health Checks sites, 'poor well-being' was higher after than before the service received (based on a small sample), probably reflecting increased strain in the caring situation, as these carers were more likely than others to care for someone whose health had deteriorated.

- Data on carers in the NHS Support sites were not available for statistical analysis, but these carers' comments about the support they received were overwhelmingly positive. Many said this was their first contact with carers' services. Both they and the staff involved felt offering additional support through carers' centres through the NHS Support site had made services accessible to a wider range of carers, including those uncomfortable with, or reluctant to approach, social services.

Chapter 6
Understanding the Cost Implications of Demonstrator Sites Services

Andrea Wigfield

6.1   Introduction

It is widely recognised that carers save the economy a significant amount of money, both in terms of the direct value of the support they provide (in comparison to the costs of health and social care services) and because the care they provide either avoids, or delays, the need for long-term care services, hospitalisation or residential support (Wanless, 2006). The economic value of the contribution carers make in the UK has been calculated to be £119 billion per year (equivalent to £18,473 for every carer in the UK)[57], a figure which rose by 37% between 2007 and 2011 (Buckner and Yeandle, 2007, 2011).

The cost of care to the health and social care system, and the contribution carers make to it, inevitably varies by the type of care provided and the care needs to be met. The Public Accounts Committee, for example, estimated the cost of dementia care to the NHS and social care to be £8.2 billion in 2009, a cost which, it suggested, would be considerably higher without the contribution of carers (Public Accounts Committee, 2010). The Committee suggested that carers supporting people with dementia save the NHS and social care over £5 billion a year (Public Accounts Committee, 2008:12). The findings of Banerjee et al (2003:1316) support this, estimating that people with dementia who have a co-resident carer are twenty times less likely to be admitted to a residential care facility within a one year period, than those without such support.

The cost savings associated with carers are often put forward in support of the business case for providing support to them. However, it is not always easy to make a direct link between investment in support for carers and cost savings or costs avoided. When commissioning the Demonstrator Sites to provide support to carers, the DH specified that it expected sites to measure the cost-effectiveness of the provision they developed. The agreements between the DH and local authorities[58] delivering the DS programme stated that:

> *The Carers Strategy Demonstrator Sites Project means a project which will develop one or more demonstrator sites to test new approaches covering one or more of the following strands as part of the implementation of the National Carers Strategy:*
>
> • *Measuring the quality and effectiveness of breaks (including cost-effectiveness) for carers;*
>
> • *Delivering annual health and / or health and well-being checks for carers; and*
>
> • *Exploring ways in which the NHS can better support carers. (DH, 2009:1)*

The need to link carer support with subsequent cost benefits for services is now stronger than ever, as pressures on public sector budgets grow in the post-2008 economic climate.

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[57] The figure is derived by multiplying the unit cost of replacement care for adults and older people, which is taken as £18 per hour (an official estimate of the actual cost per hour of providing home care to an adult by the NHS Information Centre, PSS EX1 Return for 2009-2010), by the estimated total number of hours of caring provided in 2011, as is explained in more detail in Buckner & Yeandle 2011.

[58] Because of different funding arrangements between the DH and NHS organisations, there was no equivalent written contract between the DH and the NHS-led Demonstrator Sites.

With this in mind, the aim of this chapter is to assess 'how far the different policy innovations of the DS offer scope for future cost savings in the health and social care system via improved health outcomes for carers and more sustainable caring arrangements'. This is achieved by exploring the evidence, provided by the sites, relevant to the issue of whether early investment in supporting carers results in savings later as carer health, and that of the person they support, is maintained or improved.

The chapter draws on evidence from: interviews with Expert Advisers and project staff (through the case studies and Key Actor Survey); documentary analysis; and local evaluation reports. It explores: the costs of the 25 Demonstrator sites, the numbers of carers supported for that investment and the kinds of outputs achieved (section 6.2); the range of potential cost savings that have emerged from the Demonstrator Sites (section 6.3); the nature and extent to which sites have been able to capture and quantify those potential cost savings (section 6.4); the sites' potential for sustainability followed by a summary of key findings.

6.2   Costs and outcomes of carers' services and support

The Department of Health invested over £15 million in the Demonstrator Sites programme for the duration of 18 months, which was supplemented by almost £2 million of additional funding from other sources (see Table 6.1) The 12 Breaks sites were allocated just over £8 million of DH funding, the six health checks sites were awarded just under £3 million, and the seven NHS Support sites over £4.5 million.

Table 6.1 Demonstrator Sites: total amount of funding by type of site

	Total DS funding spent	Additional funding
Carers' Breaks	£8,163,945	£1,363,668
Health Checks[1]	£2,792,630	£440,451
NHS Support	£4,618,147	£52,489

Source: QRTs. Note: [1] Excluding the Tower Hamlets site as data were not supplied.

Carers' Breaks services: costs and outcomes

Total expenditure in the Breaks sites was £9,527,613 (£8,163,945 of which was DH funding and £1,363,668 of which came from other sources), as shown in Table 6.2. In these sites, total DH spending ranged from £283,563 of DS funding in the Liverpool site (which did not use any additional funding from elsewhere) to £2,253,026 in the Sunderland site (£1,436,342 of which came from the DH). These wide variations in expenditure reflect both the variation in approaches to breaks provision and the fact that some sites were offering services which were completely new (and therefore had high start up costs), while others were building on existing infrastructure and services (see Chapter 2).

The total cost per carer supported in the Breaks sites is shown in Table 6.3 and should be analysed with care[59]. In some sites, some costs of activities were funded from other sources. Thus in the East Sussex site (where cost per carer supported was relatively low at £926), the approach for carers' breaks was to give the carer free time by providing a day centre place (or similar) for the person cared for, with the day centre place resourced from other budgets[60], and the DS budget spent only on staff

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[59] Cost per carer supported has been calculated in the same way for all sites, but does not take into account differences in infrastructure and / or resources already available in sites which were previously offering similar carer support / services.
[60] DS funding could be spent on services for carers but not on services for the person(s) they cared for.

time and infrastructure costs. In the Hertfordshire site (where cost per carer supported was the lowest at £603), the DS funding covered only the costs of the website (which was designed to enable carers to access breaks in a different way[61], and the costs of breaks was funded though the local authority adults' services budget. In other sites, elements of the breaks service may have been subsidised (perhaps in similar ways). This was difficult to assess as sites found it very difficult to report additional funds received consistently. In some sites, the cost per carer supported was high (for example in the Sunderland site it was £5,792, and in the Lewisham site it was £6,000). The Lewisham site engaged with relatively low number of carers and used social workers to direct carers to the right kinds of breaks, whose hourly costs were higher than the carer support workers used in the other sites. Carers at the Sunderland site were required to submit their ideas for a break to a panel made up of multi-agency professionals and there were very few restrictions on the types of breaks that could be taken. Each break could cost up to £500 but carers could repeatedly apply for breaks and could apply for more costly breaks subject to the agreement of the decision making panel.

The site with the lowest cost per carer supported (Hertfordshire) offered alternative care in the home and improved access to breaks provision through an on-line booking system. The costs associated with the Hertfordshire site related only to the development of a website as a means of booking breaks directly, and did not include the costs of providing the breaks (which was covered by existing service arrangements). As explained in Chapter 4, Hertfordshire tapped into databases of carers already using alternative care services, and provided support to carers using the new on-line booking system, encouraging all carers to book their breaks via this system. The Warwickshire site[62] similarly developed a website for on-line booking of breaks but, in contrast to the Hertfordshire site, targeted relatively 'hard to reach' carers and allowed carers to access the breaks provision through other off-line options.

The Bristol, East Sussex and Nottinghamshire sites all recorded costs per carer supported of less than £1,000. The latter two sites provided a similar kind of support, offering specialised short term respite care to carers of people with dementia / mental ill health (in Nottinghamshire this was only part of the service provided whilst in East Sussex it covered the majority of DS activity). The Bristol site offered a highly personalised breaks service and a wide variety of different types of breaks which attracted a relatively large number of carers, thereby keeping the cost per carer supported comparatively low.

Table 6.2 provides a detailed breakdown of the costs of different aspects of service delivery in the 12 Breaks sites. The cost of carers' involvement in planning and delivery was extremely variable (£129 to £78,230), as was the cost of carers' expenses (£990 to £100,000); despite the guidance given, this may have arisen, in part, as a result of inconsistent reporting[63]. The Management costs were very similar in all the sites, although both the Sunderland and Lewisham sites had fairly low management costs.

All the Breaks sites produced a range of outputs from the DS programme. These varied by site but often included new assessment or membership forms for carers to complete to enable them to access a break, guidance packs and manuals for staff, and information packs for carers (Table 6.3).

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[61] In Hertfordshire, the cost of the breaks may have been the 'additional funding' (£138,832), but this was not stated in documentation submitted to the evaluation team.

[62] This site faced challenges engaging with its target group of carers of people with learning disabilities, who had not accessed alternative care before. This site succeeded in supporting only 25 carers, although other project benefits were achieved.

[63] It is not known if all sites interpreted the guidance in precisely the same way. Differences in expenditure reported may sometimes reflect differences in services provided or in methods of service implementation. The local evaluation reports for Breaks' sites did not comment on expenditure on different elements of provision.

Table 6.2 Carers' Breaks sites: costs of service delivery in the Demonstrator Sites (£s)

Site	(a) Total DS funding spent[1]	(b) Direct costs of supplying services	(c) Management costs	(d) Marketing costs	(e) Direct payments[2]	(f) Carer involvement in planning and delivery	(g) Carer expenses (travel, alternative care, etc)	(h) Other costs	(i) Additional funding committed locally[3]
Bath and NE Somerset	616,822	455,500	128,160	20,897	n/a	3,650	8,615	n/a	0
Bristol	628,340	419,247	75,748	14,023	62,800	8,712	4,795	43,015	0
Derby	1,029,031	338,481	139,397	32,746	231,189	78,230	27,460	181,528	55,371
East Sussex	560,333	378,202	125,345	0	n/a	200	n/a	56,586	0
Hertfordshire	276,943	99,549	170,577	6,688	n/a	129	n/a	n/a	138,822
Lewisham	600,000	283,377	11,780	5,234	223,625	20,545	8,439	47,000	0
Liverpool[4]	283,563	#	119,907	3,444	116,818	26,428	#	16,966	0
Nottinghamshire	534,734	313,332	85,424	34,973	30,714	5,105	2,026	63,160	60,000
Suffolk	1,027,647	452,838	181,210	20,000	165,000	42,499	100,000	66,100	60,000
Sunderland[5]	1,436,342	812,382	22,000	15,109	564,659	n/a	#	22,192	816,684
Torbay	473,200	220,153	135,745	43,590	2,000	23,000	990	47,722	50,750
Warwickshire	696,990	341,890	#	8,933	#	7,804	#	338,363	242,031
ALL	8,163,945	4,114,951	1,195,293	205,637	1,396,805	216,302	152,325	882,632	1,363,668

Source: QRTs.

Notes: # Data were not supplied / not available. Figures in column (a) = sum of figures in columns (b) - (h).

[1] The maximum funding available to a single site (from the DH) was £800,000 over 18 months. At least two sites (Sunderland and Derby) appear to have under-reported the additional funding they received, as (taking into account the additional funding declared) the total expenditure in these two sites is greater than the maximum funding available from DH.

[2] Variations in expenditure on direct payments depend on whether these were a major part of site activity (as in Sunderland) or a minor aspect (as in Torbay).

[3] Sites were asked to report the sum total of additional funding committed to the site locally. Not all sites had additional funding

[4] No figure is given for the direct costs of supplying services in Liverpool as here the site was not the direct provider of the breaks.

[5] Carers' expenses are included in the direct costs of supplying services for the Sunderland site.

Table 6.3 Carers' Breaks sites: costs, outcomes and sustainability of services

Sites	Approach to Breaks provision[1]	Total cost per carer supported[2]	Carers supported (no.)	Outputs[3]	Potential cost savings evidenced in local evaluation reports[4]	Service continuing after 31st March 2011	Potential for sustain-ability
Bath and NE Somerset	B, E, F, G, H, I, J	£1,408	438	Membership form for accessing breaks.	Health and well-being, network of support.	Pending outcome of funding application	Low / medium
Bristol	C, D, E, F, G, H, I, J	£831	756	Breaks assessment form.	Care co-ordination, earlier identification illness.	In part (new approaches to assessing carers)	Medium
Derby	B, C, E, J	£1,185	915	Information packs for carers (including useful contacts sheets e.g. self-assessment forms); carer discount cards.	Health and well-being, preventing admission.	In part (e.g. personal budgets; self-assessment)	Medium
East Sussex	A	£926	605	Carers respite monitoring and feedback forms.	Care co-ordination, GP practices, health and well-being, network of support, preventing admissions, sustain caring.	Yes	High
Hertfordshire	B, J	£603	689	Booking instructions for breaks; manuals for providers and staff, staff welcome and information packs; website.	Return to work, sustain caring.	Yes	High
Lewisham	B, C, D, E, G, I	£6,000	100	Carer referral forms; carer support plan template; personal budget protocols.	Health and well-being.	Yes	Medium
Liverpool	C, D, E, H, I, J	£1,066	266	Carer breaks forms and guidance packs (including self-directed assessment forms; carer support plans; financial forms; useful contact list and individual records).	Care coordination, health and well-being, network of support, sustain caring.	Yes	Medium
Nottinghamshire	A, C,	£840	708	Carer record forms.	Health and well-being, network of support, preventing admissions, sustain caring.	No	Medium
Suffolk	A, C, D, E, G, H, I, J	£2,137	509	Carer vouchers scheme; report on capacity building programmes; website; bus to improve carers access to services in rural areas; new carer-led forum.	Health and well-being, network of support, return to work.	In part (carer-led group providing breaks / support)	Medium
Sunderland	C, H, J	£5,792	389	Carers breaks forms and guidance (including referral and breaks request forms).	Earlier identification illness, health and well-being, preventing admissions, sustain caring.	In part (personal budgets; breaks without assessment)	Medium
Torbay	B, E, J	£2,055	255	Information booklet for carers of people with dementia; evaluation questionnaires; self-assessment and support plan forms; carers forum website.	Earlier identification illness, health and well-being, sustain caring.	In part (young carers service; personalised breaks; carers centre)	Medium
Warwickshire[5]	B, J	#	25	Guide to breaks for service teams; breaks booking manuals for providers; staff and carers; website.	#	No	Low

Sources: case study interviews, local evaluation reports, site documents, quarterly calls, QRTs. Notes: [1] Approaches to Breaks provision are coded as follows: (A) Specialised short term respite (b) Alternative care in the home (C) Carers' holiday breaks funding (D) Practicing help in everyday life (E) Well-being support / services (F) Training for the caring role (G) Work related training (H) Training for other skills (I) Equipment and domestic goods funding (J) Improving access to breaks. [2] Total cost per carer supported is the total funding (DH and additional funding) spent divided by the number of carers supported. [3] In addition to the listed outputs, all sites produced a local evaluation and marketing materials. [4] This evidence is based on data from final local evaluation reports and supporting documents. Potential cost savings include: preventing hospital or residential care admissions; supporting carers to sustain their caring role; earlier identification of physical and / or mental health issues; improved health and well-being of carers; better care coordination; efficiency savings in GP practices; assisting carers to return to, or remain in, paid work; and the provision of an informal network of support for carers. The quality of the evidence presented for these outcomes varied, from anecdotes from staff and carers to systematic data from surveys, interviews, and measures of health and well-being. [5] Comprehensive data is not included for Warwickshire as difficulties in engaging carers were encountered in this site.
Data were not supplied / not available.

Health Checks sites: costs and outcomes

Total expenditure in the Health Checks sites was £3,233,081 (£2,792,630 of which was DH funding and £440,451 of which came from other sources), as shown in Table 6.4. As expected (given their different funding allocations), the cost of delivering services in the Health Checks sites varied; the Northumberland site (which did not have additional local funding) spent £229,855 on delivering the Health Checks and related services, whereas, at the other end of the spectrum, the Devon site (which had substantial resources in addition to the DS funding) spent £982,839 (£776,194 of which was DH funding). Variation in expenditure between the Health Checks sites is not as large as in the Breaks sites primarily because the Health Checks sites all offered the same broad type of provision (see Table 6.5 and Chapter 2), whereas the services offered in the 12 Breaks sites differed substantially.

Cost per carer supported in the Health Checks sites is shown in Table 6.5 and, as explained earlier, should be analysed with care. The Devon site, which offered the highest number of health checks and spent the largest amount of money, also offered the cheapest health checks per carer (at £336). The cost of the health checks per carer was highest in the Camden site (£2,336) followed by the Redbridge site (£1,463).

Both these sites offered separate physical examinations and well-being checks, whereas the other sites offered a combined physical health and well-being check, suggesting that a combined health check offers a more economical option. Costs in the Trafford site fell somewhere between these two extremes. Services were offered in a different way here than in the other sites, and were provided entirely by case workers based in the local carers' centre, under the supervision of a nurse assessor (see Chapter 2 for more details).

Table 6.4 provides a detailed breakdown of the costs of different aspects of service delivery in the six Health Checks sites and shows some notable differences in expenditure on management and marketing costs. The Devon site spent most on management and marketing, but, as already explained, also delivered the highest number of checks and contacted the largest number of carers. It also spent more than other sites on carers' expenses. While the site with the largest budget might be expected to deliver the most support, the Devon model also showed that an ambitious target was achievable (reaching 97% of its planned carer numbers, as shown in Table 4.3).

All the Health Checks sites produced a range of outputs from the DS programme. These often included guidelines / information for staff and a health and well-being booklet. The booklet was a document listing a series of questions about the health and well-being of each carer and was completed either by the carer (prior to the health and well-being check) or by the worker conducting the check, during the check itself (Table 6.5).

Table 6.4 Health Checks sites: costs of service delivery in the Demonstrator Sites   (£s)

Site	(a) Total DS funding spent	(b) Direct costs of supplying services	(c) Management costs	(d) Marketing costs	(e) Direct payments[1]	(f) Carer involvement in planning and delivery	(g) Carer expenses (travel, alternative care, etc)	(h) Other costs	(i) Additional funding committed locally
Camden	563,785	273,749	66,840	27,500	n/a	6,750	1,546	187,400	62,500
Devon	776,194	250,435	362,765	33,600	n/a	4,500	22,851	102,043	206,645
Northumberland	229,855	73,988	148,700	3,426	n/a	n/a	177	3,564	0
Redbridge	753,219	374,974	200,309	25,478	n/a	3,960	515	147,983	124,506
Tower Hamlets	#	455,630	#	#	#	163	#	#	#
Trafford	469,577	270,533	87,278	#	89,450	9,549	12,767	0	46,800
ALL[2]	2,792,630	1,699,309	865,892	90,004	89,450	24,922	37,856	440,990	440,451

Source: QRTs.

Notes: Figures in column (a) figures = sum of figures in columns (b) - (h).

Data were not supplied / not available.

[1] Direct payments were not a feature of most Health Checks sites. The Trafford site reported expenditure on direct payments, incurred in giving 'health awards' to carers (who could apply for one-off personal budgets for items relevant to better health, such as a bicycle). There was some debate during the DS programme about whether direct payments were permitted as part of health delivery (one site reported that it had not been permitted to provide direct payments as part of its service, despite this having featured in its original plan).

[2] Excluding the Tower Hamlets site as data was not supplied.

Table 6.5 Health Checks sites: costs, outcomes and sustainability of services

Sites	Approach to Breaks provision[1]	Total cost per carer supported[2]	Carers supported (no.)	Outputs	Potential cost savings evidenced in local evaluation reports[3]	Service continuing after 31st March 2011	Potential for sustain-ability
Camden	A, B, C	£2,336	268	Health and well-being booklet; list of staff competencies; guidance for involving volunteers.	Care co-ordination, health and well-being, return to work.	No (options under investigation)	Low
Devon	A, B, C	£336	2,924	Health and well-being booklet; webpage.	Care co-ordination early identification of illness, health and well-being.	Yes	High
Northumberland	A, B, C	£503	457	Health check tool, information leaflet for health care staff; primary care 'toolkit'; revised carer policies; competencies list.	Care co-ordination. early identification of illness, health and well-being, sustain caring.	Pending outcome of application for funding	Medium
Redbridge	A, B, C	£1,463	600	Health and well-being booklet.	Care co-ordination, early identification of illness, health and well-being.	No (options under investigation)	Low
Tower Hamlets	A, B, C	#	605	Health and well-being booklet.	Early identification of illness, health and well-being, sustain caring.	No (options under investigation)	Low
Trafford	A, B, C	£880	587	Life-style and well-being questionnaire; life-style and well-being guidelines for case workers.	Care co-ordination, health and well-being, sustain caring.	In part (continuing with reduced staff)	Medium/high

Sources: case study interviews, local evaluation reports, site documents, quarterly calls, QRTs.

Notes: # Data were not supplied by site.

[1] A) Physical health examination; B) Well-being check; C) Improving access to health checks.

[2] Total cost per carer supported is the total funding (DH and additional funding) spent divided by the number of carers supported.

[3] This evidence is based on data from final local evaluation reports and supporting documents. Potential cost savings include: preventing hospital or residential care admissions; supporting carers to sustain their caring role; earlier identification of physical and / or mental health issues; improved health and well-being of carers; better care coordination; efficiency savings in GP practices; assisting carers to return to, or remain in, paid work; and the provision of an informal network of support for carers. The quality of evidence presented for these outcomes is varied, from anecdotes from staff and carers to systematic data from surveys, interviews, and measures of health and well-being.

Table 6.6 Better NHS Support sites: costs of service delivery in the Demonstrator Sites   (£s)

Site	(a) Total DS funding spent	(b) Direct costs of supplying services	(c) Management costs	(d) Marketing costs	(e) Direct payments[1]	(f) Carer involvement in planning and delivery	(g) Carer expenses (travel, alternative care, etc)	(h) Other costs	(i) Additional funding committed locally
Bolton	783,857	345,245	317,937	8,675	12,000	n/a	n/a	100,000	0
Halton and St. Helens	600,225	457,025	119,005	15,780	n/a	8,415	n/a	0	0
Hastings and Rother	518,010	356,052	136,405	6,000	n/a	66	442	19,045	52,489
Northamptonshire[2]	741,089	398,170	104,785	60,950	n/a	16,339	n/a	180,845	#
South West Essex[3]	667,459	n/a	319,291	94,972	n/a	n/a	16,544	236,652	0
Swindon	723,547	202,478	40,773	50,786	#	20,495	9,267	399,748	0
West Kent	583,960	#	334,317	93,657	n/a	51,534	340	104,112	0
ALL	4,618,147	1,758,970	1,372,513	330,820	12,000	96,849	26,593	1,020,402	52,489

Source: QRTs.
Notes: Figures in column (a) = sum of figures in columns (b) – (h).
Data not supplied.
[1] Most NHS Support sites did not plan to use direct payments. In relevant cases, this is marked 'n/a' (not applicable).
[2] The Northamptonshire site was able to draw on (unspecified) additional resources in the local authority budget for carers' services to support the DS infrastructure and team. The precise amount used for this purpose was not reported.
[3] In the South West Essex site no 'direct costs of supplying services' were incurred as the site did not provide direct services to carers.

Table 6.7 NHS Support sites: costs, outcomes and sustainability of services

Sites	Approach to Breaks provision[1]	Total cost per carer supported[2]	Carers supported (no.)	Outputs	Potential cost savings evidenced in local evaluation reports[3]	Service continuing after 31st March 2011	Potential for sustainability
Bolton	C, D, E, F	£999	785	Carers' charter; training DVD; information pack for carers (e.g. definition of a 'carer'; available support; directory of services).	Care co-ordination, early identification of illness, health and well-being.	In part (training and e-learning to be continued and rolled out trust-wide, befriending service not continuing)	Medium
Halton and St. Helens	A, B, D, E	£171	3510	Carers' charter; carers' policy and guidelines; information pack for carers.	Care co-ordination, health and well-being, preventing admission, sustain caring.	Yes	High
Hastings and Rother	A, B, D, E	£538	1060	Carers' charter.	Care co-ordination, health well-being.	No (although previous hospital liaison service continuing)	Medium
Northamptonshire	B, C, D, E, F	£1,338	554	Website; information pack for carers.	Care co-ordination, network of support.	Yes	Low
South West Essex	A, B, D, E, F	£1,483	450	Pathways document; information pack for staff (e.g. how to recognise carers; service directory; referral pathways); integrated assessment documentation; website.	Care co-ordination, health and well-being, network of support.	In part (continuing on a smaller scale with reduced staff resources)	Medium
Swindon	A, B, D, E, F	£1,171	618	Carers charter; training DVD; distance learning tool; improved assessment documentation; information pack for staff.	Care co-ordination.	In part (continuing on a smaller scale with reduced staff resources)	Medium
West Kent	A, B, D, E, F	£1,007	580	Carer Policy; integrated assessment documentation.	Care co-ordination, early identification of illness, health and well-being, network of support, preventing admission, GP practices, sustain caring.	Yes	Medium

Sources: case study interviews, local evaluation reports, site documents, quarterly calls, QRTs.

Notes: [1]A) Hospital based carer support; B) Primary care based carer support; C) Voluntary sector based carer support; D) Carer awareness training for NHS staff; E) Information about / or for carers; F) Carer's Assessments: delivery and/or documentation.

[2] Cost per carer supported is the total funding (DH and additional funding) spent divided by the number of carers supported.

[3]This evidence is based on data from final local evaluation reports and supporting documents. Potential cost savings include: preventing hospital or residential care admissions; supporting carers to sustain their caring role; earlier identification of physical and / or mental health issues; improved health and well-being of carers; better care co-ordination; efficiency savings in GP practices; assisting carers to return to, or remain in, paid work; and the provision of an informal network of support for carers. The quality of the evidence presented for these outcomes varied, from anecdotes from staff and carers to systematic data from surveys, interviews, and measures of health and well-being.

NHS Support services: costs and outcomes

Total expenditure in the NHS Support sites was £4,670,636 (£4,618,147 of which was DH funding and £52,489 of which came from other sources), as shown in Table 6.6. Total DS spending ranged from £518,010 in the Hastings and Rother site to £783,857 in the Bolton site. Only two of the NHS Support sites reported any additional funding, Hastings and Rother and Northamptonshire. The former spent an additional £52,489 while the latter supplemented its DH budget with some of the local authority's funding for carers' services.

Total cost per carer supported in the NHS Support sites is shown in Table 6.7 and, as stated before, should be analysed with care. The Halton and St Helens site reported the lowest cost per carer supported (at £171) and also engaged with the largest number of carers. Costs per carer supported were slightly higher in the Hastings and Rother site (£538), but lower than in the five other NHS Support sites. The Halton and St Helens and Hastings and Rother sites offered the same approaches to service provision (carer support through hospitals and primary care; carer awareness training for staff; and information about and for carers). Cost per carer supported in the other five sites was fairly similar (£999 - £1,483).

There was considerable variation in expenditure on management and on marketing. The Swindon site spent relatively little on management (£40,773) compared to some of the other sites (Bolton, South West Essex, and West Kent all spent over £300,000 on management of the programme). Those sites which spent least on marketing (Bolton, Halton and St Helens, and Hastings and Rother) committed considerable resource to identifying carers in hospitals or in other NHS settings which, as discussed in Chapter 4, led to some success in engaging with carers (these three sites engaged with the largest numbers of carers). In these cases the cost of the staff time involved in engaging with carers appears is a 'direct cost of supplying services', rather than as a marketing cost (Table 6.6).

The amount spent on 'carer involvement' (see Chapter 4) also varied widely across the NHS Support sites: two sites reported no such costs; the Hasting and Rother site reported just £66; and the West Kent site, in contrast, reported spending £51,534. Explanations for this wide variation may be due to the different ways in which sites recorded budgetary information. Only a few NHS Support sites offered direct payments to carers, and the Bolton site was the only site to report expenditure on direct payments (the Northamptonshire and Swindon sites reported using personal health budgets for carers but appear to have included their costs under a different budget heading).

All the NHS Support sites produced a range of outputs from the DS programme. These varied by site; many produced a carer's charter, information packs for carers and / or staff, and training materials including, in some cases, DVDs (Table 6.7).

6.3   Identifying potential cost savings

Assessing the cost effectiveness of the DS has inevitably been challenging for the national and local evaluation teams. Many of the issues arising were highlighted by the national evaluation team at the outset and these were summarised in a working paper prepared for the DH in December 2009[64]. The paper confirmed that the aim of the national evaluation was *not* to 'produce a comparative assessment of performance between the 25 sites', nor to produce a 'league table' of performance measures. The paper also acknowledged that, as the sites had been informed that they 'should not be deterred from experimenting with new ideas or approaches because of the evaluation', some of the approaches taken might not, in the end, prove to be effective in delivering better support to carers. It was nevertheless envisaged (by the DH, the national evaluation team and the sites) that, whatever the outcome, good

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[64] *'Issues in measuring cost-effectiveness and ROI'*, unpublished paper drafted as an internal working document to aid discussion between the DH, the DS Expert Advisers and the national evaluation team.

quality information about what was done, at what cost, and with what barriers would be collected and that this learning would be important in guiding the future direction of relevant service developments.

Many of the 'end of programme' local evaluation reports produced by the Demonstrator Sites report that, despite an initial intention to measure the cost effectiveness or social return on investment of DS activities, it did not ultimately prove possible to do this. Explanations of the difficulties and challenges of carrying out a thorough and comprehensive assessment of the cost benefits of the DS, both locally and nationally, were outlined in Chapter 1, and included: the diversity of the support services provided; the need for an accurate and full record of all inputs and outputs; the availability of appropriate information; and the relatively short timeframe for the programme.

Evidence collected through the national and the local evaluation studies identified a number of potential cost savings which might arise as a result of the support offered in the DS programme: preventing hospital or residential care admissions; supporting carers to sustain their caring role; earlier identification of physical and / or mental health issues; improved health and well-being of carers; better care co-ordination through improved partnership working; efficiency savings in GP practices; assisting carers to return to, or remain in, paid work; and the establishment of informal networks of support among carers.

Preventing admissions to hospital or residential care

Anecdotal evidence from interviews with staff in some of the Breaks, Health Checks and NHS Support sites indicates that the services provided have the ability to prevent hospital admissions for both the carer and the person being cared for. Preventing hospital admissions for the former can, in turn, reduce the need for emergency admission to residential care of the latter. Four sites reported reduced hospital admissions in their local evaluation reports (Tables 6.3, 6.5 and 6.7). When project staff were asked about this (in the Key Actor Survey), a large minority (19/68) stated that they thought the programme had resulted in a reduction in emergency care / residential care admissions. A similar proportion stated that they did not know, reiterating the difficulties sites have had both in monitoring potential cost savings and in calculating them.

An example was provided by a member of staff in one NHS Support site who indicated that there had been a reduction in the risk of falling for the person being cared for as a result of the DS intervention, leading to an avoided hospital admission. In another similar case, a carer had been provided with 'falls' training which had reduced the risk of falling for the person they cared for (and therefore the risk of their being admitted to hospital). In another case, telecare sensors were installed in the home, enabling falls to be detected promptly, again reducing the risk of hospital admission and allowing the carer to leave the person they cared for alone for short periods.

Preventing hospital admissions through the services offered by the DS does not just concern the person being cared for but can also extend to the carer who is supported. Staff in two sites (an NHS Support site and a Health Checks site) provided examples of carers who (through the support provided) were able to avoid becoming ill themselves, thus avoiding hospital, and / or residential care admission for the person they cared for.

Avoiding 'carer breakdown' was also mentioned as an outcome of the DS, which can also result in fewer emergency admissions:

> *We're hopefully stopping carer breakdowns…You've got unplanned admissions there because of the carer breaking down...we're obviously saving the NHS money.*

A member of staff from a Breaks site made a similar comment:

> *Other definite results have been avoiding acute hospital admissions as well, which is very important...and / or acute respite admissions as well, enabling the person to cope*

longer term with the sort of demands that they're having to deal with....Prevention of acute admissions, prevention of acute respite; I think that will have a knock-on effect in the health and social care, for sure.

A survey of 77 carers who received support from the West Kent NHS Support site concluded that there had been five cases of avoided Accident and Emergency Admissions and a further four cases of reduced need for emergency replacement care (West Kent, Local Evaluation report, Appendix 13b:4-5). Similarly in the East Sussex Breaks site, interviews to assess the professional judgements of 31 care co-ordinators revealed that in 90 of 203 cases the need for emergency alternative care had been avoided (East Sussex, Local Evaluation report).

Some ways in which the DS support led to avoidance of carer breakdown (and reduced need for emergency replacement care) are exemplified in Box 6.1, provided in a Breaks site local evaluation report.

Box 6.1 Breaks can prevent carer breakdown: example

Mrs. M was supporting her husband. Her caring role was escalating by the week because of the severity of his illness (COPD). She felt overwhelmed and had had no respite of any sort for about three years. She felt that her situation was reaching a critical point where she was unable to care. She was helped to complete a Carers' Self Assessment form along with an Emergency Plan. All her concerns were identified. Her priorities were: a break from her caring role; and practical support so that she could lift and bathe her husband.

Mrs. M received a Carers' Personal Budget of £500 which enabled her to go on a week's break. Mrs. M said afterwards that this break was the only thing that enabled her to keep her sanity and prevent a physical breakdown. Support was also provided for her husband in the mornings to assist in personal care. Mrs. M is now much happier and secure because of this. She says that she feels she has been really supported and listened to as a carer.

Source: Derby, Local Evaluation report: 37.

Preventing hospital admissions has clear cost saving implications. Costs avoided may include: £95 for a simple accident and emergency attendance; £345 per 24 hours for a short hospital inpatient stay; £1,571 per 24 hours for a long inpatient stay (PSSRU, 2010). Such costs savings may not necessarily materialise immediately, and in the short term costs may increase while preventative care support is provided (such as falls training or a delayed hospital discharge). This was an issue mentioned by staff in two NHS Support sites and in the Halton and St Helens Local Evaluation report.

Sustaining the caring role

In addition to avoiding carer breakdown, there was also evidence that the DS activities enabled some carers to continue caring for longer, thus avoiding the need to place the person cared for in costly residential care. This was particularly the case for the Breaks sites, as Table 6.3 shows, with six Breaks sites reporting evidence in their local evaluation reports that carers were able to sustain their caring role for longer. This is exemplified in the local evaluation report of the Liverpool site which suggests that the breaks service supported carers to continue to care, reducing the need for more expensive residential care or other community support services. The report points out that supporting carers effectively to continue to provide care can be far less expensive and the preferred option for many families (Liverpool, Local Evaluation report). The costs of residential care to the state are very large. Of the £15.3bn spent

on adult social care in 2007-8, 48% was spent on residential care (Health and Social Care Information Centre, 2009) with costs for residential care on average £559 per week per adult (CSCI, 2008).

Two Breaks sites (Liverpool and Nottinghamshire) attempted (through their local evaluations), to collect evidence, using a survey of participating carers, of the extent to which their service had enabled carers to sustain their caring role for longer. The research for the Liverpool site concluded that, of 75 carers who responded to a monthly outcomes survey in March 2011, two thirds felt more able to cope as a result of accessing the service. The research for the Nottinghamshire site collected data on 111 individual cases and reported that 75% of respondents said they felt better able to continue caring since receiving the service. Similar supporting evidence is provided in the local evaluation evidence of the East Sussex Breaks Site. There, care co-ordinators provided detailed reports on the cases of carers who had accessed a break. Many felt the programme had a significant impact on enabling carers to cope with their caring role for a longer period of time (East Sussex, Local Evaluation report).

Site staff gave many qualitative examples of individual cases of carers who said they would not have felt able to continue to care without the break, both in the national evaluation interviews with site staff and in the local evaluation reports. In the East Sussex Breaks site (which provided short term respite care for people with dementia), several carers felt the support had enabled them to cope with their caring responsibilities and were unsure how they would continue providing care without support from the programme. For example, one older female carer (80+) with significant health issues, had been struggling with her caring role and claimed in a follow-up interview that if the short breaks were to be withdrawn: *'that would probably be more or less curtains.'* Another female carer (who gave her age as 55-65) stated that she was very worried about how she would cope if the support was discontinued, as her husband was reluctant to use other services: *'I would have thought it would be going back to how it was I suppose, especially if he won't go to the day centre. I think it would be a bit grim.'* (East Sussex, Local Evaluation report: 26).

A similar example was provided by a member of staff from another Breaks site:

Box 6.2 Breaks can support carers to continue caring: example

A man who looks after his parents has a mother who has mobility problems and becomes confused, and a father who has dementia. The son moved in to look after them and really struggled to deal with his father. The son was getting very wound up, frustrated and depressed. The site was contacted via social services and was able to provide the son with a three hour break once a fortnight. The son says that has been enough for him to be able to 'do his own thing'. His mother now goes to a day centre and the site support worker takes his father out, and this gives the son time for himself, which is all he wanted. If this break was not provided it is likely that the mother or father (or both) would have to go into care, with large additional costs to the social care system.

Source: Key Actor Survey (follow-up interview).

Many examples of carers who felt able to continue caring were mentioned in the local evaluation reports for the Breaks sites. Similar examples were also provided of carers accessing both Health Checks and the NHS Support service. In the Trafford Health Checks site, for example, one of carers stated:

> *It's helpful to know where to go when very stressed. Blood pressure relieved immediately after session – this occurred at a time when my husband was very ill ...support has made it possible for me to continue to care for my husband at home.*
> *(Trafford, Local Evaluation report: 10).*

The local evaluation report for West Kent, an NHS Support site, made similar claims (without specific examples), suggesting that *'carers reported that they felt supported and better able to continue in their caring role following CSW (Carer Support Worker) intervention'* (West Kent, Local Evaluation report:4). In another NHS Support site, Halton and St Helens, a hospital based income maximisation officer provided benefits advice which the local evaluation report suggested led to 233 carers submitting applications for benefits, with £1.3 million of benefits and awards obtained by carers. The average amount per week that carers were better off as a result of the new benefits awarded was reported to be £112.13 (equivalent to £5,831 per annum per carer supported) and this, the local evaluation report concluded, reduced the financial hardship faced by carers and enabled many of them to continue caring for longer (Halton and St Helens, Local Evaluation report:8).

Many of the local evaluation reports and interviewees mentioned above viewed the ability of carers to continue to care for longer and sustain their caring role following the DS intervention as a cost saving measure. As one staff member in a Breaks site stated:

> *It must do [save money for the wider health and social care system]. It must do, in terms of admittance for residential care. I know that we prevented that and delayed it and also facilitated it happening more smoothly when it does happen.*

Another staff member, in a different Breaks site, said:

> *At a more high level, breaks act as an early intervention, a preventative tool as it stops carers from requiring more expensive support it reduces the weight on the wider health and social care system.*

In the Liverpool Breaks site, in particular, the cost of the alternative care to the local authority while the carer had a break was negligible, as supporting families were encouraged to offer to provide alternative care while the carer had a break. The local evaluation report for this site suggests this was often the preferred choice of the carer and the person being cared for.

In some cases, although the DS intervention may have enabled the carer to carry on caring in the short term, the support provided to carers may simply have delayed admission to residential care of the person they cared for. Where admission to residential care has been delayed, although cost savings are made in the short term, it must be accepted that the cost of residential care will probably still arise albeit at a later date.

Earlier identification of physical or mental health issues

One of the key hypotheses of the DS programme was that undertaking health and well-being checks and identifying undiagnosed conditions could provide significant cost savings if, and where, long-term conditions are diagnosed early and more expensive medical interventions are avoided. Some sites, such as Torbay (a Breaks site also offering health checks), targeted disadvantaged groups (younger carers and carers from ethnic minority communities) with a view to carrying out health checks with those at a higher risk of ill-health so that health issues could be identified earlier, saving money in the longer term by avoiding the need for costly treatments (Torbay, Local Evaluation report).

A selection of DS staff were asked, through the Key Actor Survey, if they thought that earlier identification of physical or mental health issues among carers had improved following the DS activity. The majority (41/68) stated that they thought it had. Unsurprisingly, interviewees from the Health Checks sites were more likely to mention this as a particular potential cost saving (19/26) than those interviewed in either the Breaks (10/26) or NHS Support sites (11/16). In interviews, site staff mentioned various health issues that had been diagnosed through the health checks, including: diabetes; depression; high blood pressure; high cholesterol; and cancer. Earlier identification of physical or mental health issues was identified as a key outcome in a number of the sites' local evaluation reports (Tables 6.3, 6.5, 6.7).

Some of the Health Checks sites collected data on the proportion of health checks which led to diagnosis and further medical intervention and presented this in their local evaluation reports. In the Health Checks site in Northumberland, for example, 24% (60/252) of carers who had a health check and whose information was analysed were referred to a nurse for a follow-up appointment, with a similar proportion, 23% (59/252), referred to a GP for a follow-up appointment. A wide range of referrals to other services was also reported, including to: vision; hearing; oral health; podiatry; smoking; alcohol; and safeguarding services for 22% (56/252), of the carers supported (Northumberland, Local Evaluation report:13). The local evaluation report for the Devon site reported that, of the health and well-being checks carried out (which also counted as a Carer's Assessment), 66% (1,644/2,510) led to further NHS referrals (including GP and practice nurse appointments, phlebotomy, stop smoking service, a screening programme, health trainers, community nursing, check-ups for dentistry, opticians, audiology). Furthermore, 47% of carers who received a health check received a vascular risk assessment as part of the check and significant levels of onward referrals for further investigations and treatment were recorded (Devon, Local Evaluation report, Appendix 2: 2; Section 1: 4). The Tower Hamlets site reported in its local evaluation report that the health checks identified a large proportion of carers (66%) with pre-high, high or low blood pressure. These carers were then referred for preventative support or further treatment (Tower Hamlets, Local Evaluation report: 49).

The local evaluation report for West Kent, an NHS Support site, reported that of over 600 carers across hospitals and GP practices in contact with the service, two-fifths were signposted for further intervention, with the health checks enabling the early identification of chronic disorders for a small number of carers (West Kent, Local Evaluation report). The Bolton NHS Support site similarly reported in its local evaluation that 77 referrals were made following the health checks including for weight management, smoking cessation, primary care mental health services and to local carers' services (Local Evaluation report, Bolton).

While some sites were able to map the proportion of further referrals as a result of the health checks, calculating the cost savings associated with this was a challenge for most. The NHS Support site at Bolton identified this difficulty in its local evaluation report, concluding that between June 2010 and March 2011 approximately 71% of those referred went on to receive an assessment but that there was inadequate data to calculate cost benefit analysis (Bolton, Local Evaluation report). In the West Kent NHS support site local evaluators produced a table of perceived cash-releasing impacts which goes some way to identifying specific referrals (following the support) where a cost benefit is identifiable. This found four cases of early identification of chronic conditions in a survey of 77 carers (West Kent, Local Evaluation report, Appendix 13b:4).

Improved health and well-being of carers

All three types of site in the local evaluation reports (Tables 6.3, 6.5, 6.7) reported examples of improvements in carers' health and well-being following the DS intervention. It is widely acknowledged that well-being has a profound bearing on health but, as the Northumberland local evaluation report indicates, well-being is *'typically overlooked until carer health fails and substantial and expensive intervention is required'* (Northumberland, Local Evaluation report:3). Maintaining the health of carers through the provision of appropriate well-being support at an early stage, combined with regular targeted health checks, can delay the onset of health problems and enable carers to maintain their caring role for longer than would otherwise be the case, reducing the need for costly residential care for the person they care for (as explained in the previous section). Some sites provided specific kinds support with health and well-being in mind, for example eight Breaks sites offered health and well-being services (see Chapter 2) such as gym membership fees, alternative therapies, and stress management support. The Camden Health Checks site, in additional to carrying out the health and well-being checks, referred carers to local health initiatives for eight-week courses with exercise specialists.

Nine of the 12 Breaks sites, all of the six Health Checks sites and five of the NHS Support sites provided evidence in their local evaluation reports to support their claim that the health and well-being of carers improved following the intervention. In the Sunderland site (a breaks provider), for example, feedback from a carer focus group revealed that all participants felt their well-being had improved and that it was easier to continue in their caring role as a result of receiving their break / opportunity. While the impact of the break on their well-being varied, it generally lasted around one to two weeks. In one case, a carer was able to purchase a bike through the programme which meant he could enjoy a break away from his caring role on a regular and sustained basis (Sunderland, Local Evaluation report). The Torbay (a breaks provider) local evaluators used the GHQ-12 (General Health Questionnaire) before and after providing the service to carers and reported a highly significant reduction in distress amongst carers during the time they received the service, as well as highly significant reductions in distress for carers overall (Torbay, Local Evaluation report). At the Liverpool Breaks site, the local evaluation reported that of 75 carers who responded to a monthly outcomes survey in March 2011 almost half (37/75) felt that accessing the service had greatly or slightly improved their health and well-being during that month. In Bath and NE Somerset, 88% of carers who had rated their health and well-being as poor prior to accessing a break through the site rated their health and well-being as good or adequate following accessing a break / activity / opportunity (Bath and NE Somerset, Local Evaluation report: 5). Similarly in the Nottinghamshire site there was a statistically significant increase in the quality of life scores from a mean average of 63.76 to 69.43 (taken from 77 carers completing a questionnaire before and after a break) and there were also improved scores when carers where asked about five statements relating to stress and carers (Nottinghamshire, Local Evaluation report: 14). The Lewisham local evaluation reported similar findings, suggesting that in a survey of carers involved in the project and a control group, higher proportions of carers reported reduced stress levels and higher levels of general health levels following a break, although small sample sizes mean that these figures need to be interpreted with caution (Lewisham, Local Evaluation report: 11).

In the Health Checks sites, in Camden (for example) 68% of a sample of 117 carers scored improved well-being on the WHO-5 index[65], while a comparator group of 101 carers showed no significant improvement in well-being over the same time period. Partners and programme staff, when asked about the potential impact on the health and well-being of the carers, reported similar results, with 78% of partner self-assessments and all project staff who were interviewed (out of 37 and 13 responses respectively) indicating that they thought the project had helped support the health and well-being of carers (Camden, Local Evaluation report: 24-25). The local evaluation report for Trafford concludes that carers identified immediate and longer term health and well-being outcomes as a result of support provided, with 26% of carers reporting a clinically significant improvement in their anxiety levels at a six month health check review, and 20% of carers reporting a clinically significant improvement in their depression levels at a six month health check review, based on a sample of 177 carers (Trafford, Local Evaluation report).

West Kent, through the NHS Support provision, concluded that 63 of 77 participating carers interviewed benefitted through an improvement in well-being (West Kent, Local Evaluation report: appendix 13b:4-5); 35% of 231 carers who responded to a survey in the Halton and St Helens NHS Support site also reported that they were less stressed following their involvement in the programme (Halton and St Helens, Local Evaluation report).

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[65] The WHO-5 index is a positive psychological well-being index which covers positive mood (good spirits, relaxation) vitality (being active and waking up fresh and rested), and general interests (being interested in things) (www.who-5.org/). The findings presented in the sites' local evaluation reports are not mirrored in the results of the national evaluation, which show an increase in 'poor well-being' between the first and second waves of the surveys. As highlighted in Chapter 5, this cannot be read as an outcome of the services received. The time gap between the service and the administration of the relevant questionnaire may be important. There was a four-month gap in the national evaluation. Practise in the local evaluations may have varied.

Anecdotal evidence from the evaluative interviews with project staff also supported the positive correlation between provision of a break and / or health check and an improvement in carer health and well-being, as shown in Box 6.3.

Staff interviewed for the national evaluation study sometimes made a link between improved health and well-being and cost savings, although they were often unable to supply any cost calculations or financial evidence, as a Breaks site interviewee explained:

> *People need a break from their very long job. It is crucial to their health and well-being. Good to have it available for people. It helps people's well-being, good for their health. It prevents carer breakdown and attendant costs to their services. Preventative work is cost effective. It does prevent burn out.*

Box 6.3 Breaks can improve carers' health and well-being: example

A lady who is caring for her elderly father was meeting all his support needs as he is refusing any services. Although there is a good support network around via neighbours which gives peace of mind she does not like to go too far and her father will not go out. The impact to her health and well-being was considerable and she had been feeling tired, depressed, isolated, stressed and suffering from low self esteem and insomnia which was also impacting on the relationship with her father. Although she had previously received a Carer's Assessment and was accessing the carers' centre as a result, this was not close by and she wanted to access health and well-being services closer to home. She used her budget to purchase a bike which she uses to go round the park over the road and a gym pass for a gym nearby. Having access to the equipment and gym has enabled her to set time aside for herself to something that she values and there has been a huge change in her health since accessing the service. She no longer feels tired or depressed and feels more able to continue with her caring role, thus the cost of the carers' budget has supported the family without the need for more costly social care services for her father.

Source: Liverpool, Local Evaluation report: 21.

Better care coordination through improved partnership working between organisations

Some of the site staff interviewed through the Key Actor Survey (and the Expert Advisers) felt that the DS programme generally led to improved partnership working between organisations such as the NHS, local authorities and the voluntary and community sector and that this had promoted better working relationships and co-ordination, improved signposting, and more effective referral processes (see Chapter 3 for a more detailed discussion). The majority (44/68) of the respondents to the Key Actor Survey stated that working relationships and co-ordination between the NHS, carers, and voluntary sector organisations had improved following the DS, and also that the processes for identifying, registering and referring carers for the future had been enhanced (53/68). Staff from some sites, for example, suggested that the health checks had often led to the identification of additional support required by carers, such as further medical intervention, training, financial and benefits advice, and counselling, with carers subsequently being signposted to a relevant provider organisation.

Improved partnership working can also lead to better care co-ordination. Working together has the potential to generate cost savings in a number of ways: resource inputs from different organisations can be pooled; duplication of services by different agencies can be avoided; take-up of existing services can be higher as carer awareness improves; new pathways are developed which help prevent re-admissions and patient / carer breakdown; and carers are signposted to other support services which

means that they can be supported to care for longer, possibly avoiding the need for residential care for the person they care for. Some local evaluation reports provided evidence of improvements in care co-ordination (Tables 6.3, 6.5, 6.7); however, few of the reports make direct links between these and cost savings. One exception to this was the Liverpool Breaks site's local evaluation report, which highlighted the cost-benefits of greater carer take-up of services and suggested that one of the cost savings achieved by the service was that 'it improved access to services already commissioned for carers and other universal services' (Liverpool, Local Evaluation report:19).

Efficiency savings in GP practices

Evidence from the interviews with site staff and from the local evaluation reports indicates that the DS activity may have led to efficiency savings within GP practices. This was particularly mentioned in the interviews with those working in the Breaks sites, with regard to patient appointments, who reported fewer DNAs (Did Not Attend). In one site the breaks provided enabled carers to attend appointments while alternative care was provided for the person they cared for, as a member of delivery staff explained:

> *We also support people going to GP appointments and mental health specialists as well, so the support workers will do the sitting service to help people to actually attend appointments so there are less missed appointments, that is both to the NHS and the social services.*

West Kent, in its local evaluation, interviewed 77 carers to assess the impact of the DS on carers and identified a reduction of five DNAs (West Kent, Local Evaluation report, appendix 13b:5).

The cost savings achieved by reducing DNAs extend beyond the immediate costs of a missed appointment to the GP practice. Helping carers to attend important GP or hospital appointments can assist in maintaining the health and well-being of the carer, reducing carer visits to the GP (as identified in the local evaluation report of the Health Checks site at Tower Hamlets), identifying and treating health issues earlier and potentially avoiding more costly medical intervention at a later date (as mentioned above), which can, in turn, enable the carer to continue caring for longer, avoiding carer breakdown, thus potentially preventing the person cared for being admitted to residential care.

Assisting carers to return to, or remain in, paid work

There is some, albeit limited, evidence that the DS have enabled carers to return to, or remain in, paid work. This is particularly evident through the provision of breaks which can assist carers to carry on working or take up work, reducing their need to claim state benefits and having the potential for cost savings in other parts of the wider public sector. An example is presented in Box 6.4.

Another example was provided by a member of staff in an NHS Support site, through the Key Actor Survey. This concerned a carer who could not leave her husband alone because he was at serious risk of falling. As a result of the DS service she was referred to telecare and had sensors installed and can now work part-time. Young adult carers can particularly benefit by being assisted to remain in, or return to, paid work or education and the local evaluation results from the Camden Health Checks site indicate that this group of carers said 'the most useful well-being support services were practical help and signposting for job searches and applications (including work experience placements), further education and training' (Camden, Local Evaluation report: 6).

The cost savings of assisting carers to remain in, or return to, paid work are potentially very large. Yeandle et al (2007d) showed from a survey of carers not in paid work that more than half said that working was not possible because of the lack of suitable services available to look after the person they cared for. Later research estimated that carers miss out on an estimated £750 million to £1.5 billion in earnings which is a vital potential contribution to the economy (Buckner and Yeandle, 2011).

Box 6.4 Breaks can assist carers to remain in work: example

Kelly is a 29 year old woman with mild learning disabilities. For many years her mother used to be able to go to work and leave Kelly on her own. Following a move to a new house, Kelly started spending time with some of the local youngsters and it became increasingly clear that she was vulnerable and at risk in their company. Early last year Kelly became ill and spent a couple of months in hospital. Whilst she was ill she lost all her confidence and with the combination of circumstances Mrs Ryder felt that she could not return to work and leave Kelly by herself. Fortunately, Kelly's social worker referred the family to BookyourownBreaks.com and Mrs Ryder started using the system on a regular weekly basis. This gave her enough confidence regarding Kelly's well-being to remain in her job. Now, when holiday times come around Mrs Ryder can also use the Internet system to change the days on which she has a respite carer popping in. In the early days Kelly did not want to go out much. Now Kelly enjoys going out shopping and dog walking with the care support worker. Indeed joint interests have evolved as a result of the continuity and time Kelly and the care support worker have spent together, building up a relationship of trust and confidence.

Source: Hertfordshire, Local Evaluation report: 15.

Provision of an informal network of support among carers

An additional way in which DS activity may lead to cost savings is through the development of informal networks of support for carers, which can reduce the need for alternative support, as discussed in some local evaluation reports (Tables 6.3, 6.5, 6.7). For example, this benefit was noted in the Liverpool Breaks site, where the local evaluation report concluded that by accessing the DS service and meeting other carers and / or people in the community, carers had been able to build up their own local support mechanisms with other carers (Liverpool, Local Evaluation report:19). In this site, friends and relatives were used to provide replacement care so that the carer could have a break without incurring the costs of replacement care. The evidence indicated that the process of helping carers to think about themselves and the impact of their caring role had *'often helped other family members to recognise that their support was needed'* (Liverpool, Local Evaluation report: 19).

6.4   Calculating the cost benefit

Having discussed the potential cost savings of the DS programme, as perceived by site staff and through evidence in the local evaluation reports, this section explores the level of success sites had in attempting to quantify and calculate cost savings, and reports some of the results of this work. Analysis of the sites' local evaluation reports revealed that a small number of sites had included calculations of the cost savings associated with the DS intervention, four of which have been selected for analysis here: Derby, East Sussex and Sunderland (all Breaks sites); and Halton and St Helens (NHS Support). A summary of the methods used, as well as the key findings of these four sites is provided in Table 6.8.

The calculations made in the Sunderland site suggest that by providing a break to carers in receipt of intensive home care packages (of more than 10 hours a week) permanent admission to care within the next two years can be avoided, leading to potential savings. These calculations are based on avoidance of admission to residential care in the next two years (note that the DS intervention operated for a shorter period which led to difficulties in calculating this figure). As there was no matching of carers to quantify these cost savings, it is possible (and may be likely) that the caring situations of those who benefited from the DS breaks provision differed from those used in the baseline data (for 2009).

The East Sussex site estimated a 50% reduction in demand for intensive health and social care services as a result of the DS intervention, based on the professional judgments of care co-ordinators. If these judgements were made on the basis of a different pattern of emerging outcomes for the carer and the cared for person than is usually the case (without receipt of a breaks service) then these cost savings could be significant findings for the DS programme, particularly in relation to carers of people with dementia (who were the main beneficiaries of the service at this site). However, the robustness of these calculations is determined by the extent to which other factors have been taken into account and by how the number of instances of avoided interventions (such as sections under the Mental Health Act, hospital, residential and nursing care home admissions) were estimated (details were not provided in the local evaluation report).

Based on the estimates in Buckner and Yeandle (2011) of the economic value of the contribution made by carers, the local evaluation report for the Derby site argues that cost savings have been made in the statutory sector and it is claimed that providing a three-hour break enables carers to continue caring. However, without evidence that the breaks enabled carers to continue caring for longer (which is not presented) it is difficult to validate this claim.

The Halton and St Helens site estimated that the value added of referring 1,196 carers (of the total 3,510 carers supported by the site) to the St Helen's Carers Centre has already provided added value gains of more than £10 million and that the lifetime added value of all 2,300 carers that were referred to carers' centres by the site would be £38.8 million. These calculations have been made by extrapolating their local evaluation data based on calculations produced by a return on investment exercise undertaken by the Princess Royal Trust for Carers (PRTC) and Baker Tilly (PRTC and Baker Tilly, 2011) which concluded that each carer supported by a carers' centre results in a lifetime gain of £14,279 per carer, with 60% of this gain appearing in the first year (Halton and St Helens, Local Evaluation report: 18).

The seven NHS Support sites collaborated through the NHS Institute for Innovation and Improvement to commission Tribal (a consultancy company) to develop a tool to calculate the future costs and benefits of carers' services (as opposed to the costs and benefits of the DS activities themselves). The tool involved using a detailed questionnaire (completed by carers), and each NHS Support site committed to applying the tool locally. Difficulties arose in using the system for this kind of intervention, however, and in the end, the NHS Support sites were unable to use the tool effectively. In its local evaluation report, Swindon notes that it plans to develop the cost benefit measures and may adopt the tool (or something similar) for longer term use (Swindon, Local Evaluation report). Staff in the Northamptonshire site indicate that some calculations have been produced using the Tribal tool, but note that the complexities of the data mean reporting has taken much longer than anticipated. Staff at Redbridge, a Health Checks site, attempted a cost benefit analysis by comparing a group of participating carers and persons being cared for with a control group (not receiving Health Checks). They took into account risk scores, risk tiers, gender and ethnicity and looked at inpatient and outpatient activity of both the carer and the person cared for six months prior to and after the date the carer had the health check. They also calculated the costs, for the same two time periods, of carers' acute hospital interventions before and after the health check. The main relevant conclusion from this research was that there is a consistent upward trend in first outpatient appointments, across the risk tiers for carers. This suggests that carers who received a health check were referred on for further investigations and that this may not have taken place had the health check not been carried out, thus potentially leading to early intervention and the avoidance of later, more expensive medical care. Nevertheless, as in many other sites, Redbridge was unable to use this data to calculate the cost savings for the health checks (Redbridge, Local Evaluation report).

Evidence supplied through the local evaluations shows, therefore, that few sites calculated cost savings and that those which did often struggled to produce robust data, making further extrapolation difficult.

6.5   Potential for sustainability

Many of the sites are continuing to provide the kinds of carer support and services that were offered under the Demonstrator Sites programme, with four Breaks sites, one Health Checks site and three NHS Support sites continuing to offer a service after the DS funding ceased at the end of March 2011 and a further nine sites (five Breaks; one Health Checks, and three NHS Support) continuing to offer the service in part[66] (Tables 6.3, 6.5, 6.7). The national evaluation team made an assessment of each site's potential for sustainability based on the type(s) of approach adopted, the total spend and number of carers supported, the outputs and outcomes and whether the DS service (or elements of the service) continued beyond 31st March 2011 (when the DS funding came to an end). Two Breaks sites, East Sussex and Hertfordshire, were viewed as having a high potential for sustainability, both had relatively low overall costs and costs per carer supported and continued the service beyond the DS funding (Table 6.3). The Hertfordshire site produced various outputs (including a website) which can be drawn upon for further carers' support services and reported evidence of assisting carers to return to, or remain in, paid work in their local evaluation report. The East Sussex site (which produced short term specialised respite care to carers of people with dementia) demonstrated positive outcomes, in its local evaluation report, in a number of areas (better care co-ordination, improvements in health and well-being, a network of support among carers, prevention of hospital / residential care admissions, supporting carers to sustain the caring role, and efficiency savings in GP practices). One Health Checks site (Devon) and one NHS Support site (Halton and St Helens) also have the potential to be sustainable. The former: engaged with almost 3,000 carers; offered health checks at a relatively low cost; demonstrated resulting improvements in carers' health and well-being in its local evaluation report; and continued the service following the end of the DS funding (Table 6.5). The Halton and St Helens site engaged with the largest number of carers of all the 25 Demonstrator sites, had the lowest cost per carer supported, produced a series of outputs, identified positive outcomes in terms of avoiding hospital / residential care admissions, improving carer health and well-being, sustaining the caring role, and better care co-ordination and continued to offer the service following the end of the DS funding.

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[66] Two other sites (one Breaks site and one Health Checks site) were waiting for the outcome of funding applications at the time the report was written.

Table 6.8 Methods and results of calculating cost savings – examples from four Demonstrator Sites

Site name (type)	Method of calculating cost savings	Summary of cost savings calculated
Sunderland (Breaks)	Calculation of the number of persons cared for who have avoided admission to residential / nursing care because of the provision of intensive home care, which resulted directly from the carer having a break and the case of the person cared for being identified by the Adult Social Care service.	42 carers caring for 46 people have received an ongoing service from the Adult Social Care service, seven of whom received intensive home care packages (more than ten hours a week) and none of the cared for persons have been admitted to permanent care since the carers' break. From an analysis of people receiving intensive home care packages from Adult Social Care in 2009, it is estimated that 20.6% of people were admitted to permanent residential / nursing care within the subsequent two years. Thus, based on the seven people receiving intensive home care packages, there is potential that the carers' break could have assisted in the prevention of at least one permanent admission to care within the next two years. Based on an average gross unit cost for an older person supported in residential care of approximately £420 per week, leads to a potential saving of £21,840 per year. Data extrapolation indicates that had all 389 carers who have received a break been known to the Adult Social Care service, an estimated 59 persons being cared for would have received intensive home care, which would have assisted in avoiding 12 admissions to permanent care over the next two years, with a potential saving of £262,080.
East Sussex (Breaks)	Carried out qualitative interviews to collect the professional judgments of 31 carer co-ordinators (who were responsible for 203 service users in two of the five sites) to assess the extent to which intervention led to prevention or delay in the need for residential health and social care services. Also carried out qualitative interviews with 20 carers before and after intervention and interviewed other project staff.	Concludes that in 101 of the 203 cases (50%) demand for intensive health and social care services reduced. This produced significant cost savings which were calculated as £762,596 resulting from the work of two of the five teams between October 2009 and August 2010. Cost savings were calculated for the following interventions avoided: MHA sections; hospital, residential and nursing care home admissions; weeks in residential care; DNAs avoided; and service user contributions saved. A full breakdown of the estimated cost savings is provided in Appendix C.
Derby (Breaks)	Local evaluation report compares cost of providing breaks against Carers' UK calculation of cost of caring to the health and social care system.	The cost of a carer providing care for one hour of care a day is estimated to save the statutory sector care services £6,570 per year (based on £18 for one hour of care), which equates to £52,560 a year for a full-time carer (based on the carers caring for eight hours a day). 1,068 breaks of three or more hours in duration were provided for 915 carers at an average cost of £370, (average unit cost per break was £317). An assumption is then made that this means that there are major savings for 'statutory care services'.
Halton and St Helens (NHS Support)	Data extrapolation based on calculations made by PRTC and Baker Tilly (2011) of added value of referring carers to a carers' centre.	PRTC and Baker Tilly (2011) estimate that each carer supported by a carers' centre produces a lifetime gain of £14,279 per carer, with 60% of this gain occurring in the first year. 2,300 carers were identified by the site and referred to carers' centres, equating to £32.8 million, with over £19.7 million already gained (over £10 million of which has already be gained by referring 1,196 of the 2,300 carers to the Halton and St Helens Carers' Centre).

Sources: Local Evaluation reports for the Demonstrator Sites at Derby; East Sussex; Halton and St Helens; and Sunderland

Key Findings

Through the DS programme, the DH was seeking to gain a better understanding of which models of delivery and which kinds of carer support are cost effective, both in terms of their direct provision and in terms of wider potential cost savings in the health and social care system.

- Total overall site costs and cost per carer supported varied substantially by site both within and between the three different types of site (Breaks, Health Checks and NHS Support).

- All three types of carer support (Breaks; Health Checks; and NHS Support) have the potential to deliver cost savings, both to the providing organisation and to the health and social care sector.

- Potential cost savings identified through the national and local evaluations include: preventing hospital or residential care admissions; supporting carers to sustain their caring role; earlier identification of physical and / or mental health issues; improved health and well-being of carers; improved partnership working; efficiency savings in GP practices; assisting carers to return to, or remain in, paid work; and the benefits of informal networks of support among carers.

- Providing robust evidence in the form of quantifiable costs savings was a major challenge both for the national evaluation team and for the local site evaluators, but three Breaks sites (Derby, East Sussex and Sunderland) and one NHS Support (Halton and St Helens) made some progress in calculating the cost savings of their service using different approaches. In all four sites positive cost savings were reported.

- Many sites continued to offer all or part of the carers' support services provided within the DS programme despite the Department of Health funding coming to an end. Four sites: East Sussex and Hertfordshire (Breaks); Devon (Health Checks); and Halton and St Helens (NHS Support) developed carers' services which have the potential for sustainability in terms of the type(s) of approach adopted, total expenditure and number of carers supported, the outputs and outcomes and whether the DS service (or elements of it) continued beyond 31st March 2011 (when the DS funding came to an end).

- To evaluate the cost savings of future programmes of health and support, not only to carers but to other groups in society, careful consideration needs to be given to building tools for measuring cost effectiveness into programme design.

- A key challenge for the future is to identify mechanisms for calculating the cost effectiveness of health and social care support in an environment which is constantly changing and where individual experiences are influenced by a variety of interconnecting factors.

Chapter 7
Building Carers' Services in the Future

Sue Yeandle

7.1   Introduction

The 25 Demonstrator Sites whose activities are the focus of this report were tasked with using additional resources (a total of £15.6m) to deliver more effective, efficient and personalised ways of providing support for carers using three broad approaches – enhanced breaks services, health and well-being checks and better NHS support. The purpose of the DH funding was to enable local authorities, NHS organisations, and voluntary and community organisations - working in partnership - to demonstrate (a) what kinds of innovations, adjustments and collaborations deliver real improvements in outcomes for carers; (b) to understand how easy or difficult it is to achieve such improvements and what changes and adjustments are involved; and (c) to collect evidence about the financial and other costs and benefits of the innovations and service changes involved and their future implications for health and social care in England.

Preceding chapters have mapped the service developments and innovations implemented in the 25 DS, and explored the delivery processes involved, the steps taken to engage and support carers, the achieved outcomes for carers, and the cost implications of the services delivered. This chapter looks to the future, highlighting the changing and challenging policy context in which services for carers in the future need to be planned and implemented (section 7.2); summarising the evidence-based conclusions signalled in earlier chapters in the report (section 7.3); and presenting policy recommendations based on the evidence collected (section 7.4).

7.2   Supporting carers: the policy context

As discussed in Chapter 1, the policy context in which the 25 DS operated in 2009-11 was one of very significant change and challenge. Since the end of the DS programme, which ran from autumn 2009 to spring 2011, that situation has continued to change with an expectation of further significant developments in the near future. Developments include: implementation of the 2008 Health and Social Care Act; a change of government, with a Coalition Government in place since May 2010; implementation of the public spending decisions announced in the November 2010 Spending Review; continuing debate about the health and social care system, related to the discussion paper 'Liberating the NHS: legislative framework and next steps' (DH, 2010c) and the Health and Social Care Bill 2011; the Law Commission's report on Adult Social Care (Law Commission, 2011); and the report of the Commission on Funding of Care and Support (2011).

The 2008 Health and Social Care Act, which created the Care Quality Commission (CQC) as a single regulator across health and social care (as part of a series of measures designed to modernise and integrate arrangements for delivering health and social care services), came into force in 2009. Reporting on the 'State of Care' in England in 2010, the CQC set out what carers (as well as service users) can expect of the health and social care system in England and presented its assessment of how well the system was working (CQC, 2010). Carers, it noted, have rights which include the right to expect that they will: be treated as 'expert partners' (p19); have 'clear information and support' (p32); 'fair access' to support and services (p34); and that their views and experiences will play a role in shaping services (p38). The CQC's assessment of how the health and social care system was performing for carers was broadly positive. It assessed many councils as 'good' or 'excellent' in relation to the support they

offered carers and presented evidence of growing numbers of carers receiving direct payments (p54). Nevertheless the CQC drew attention to various weaknesses in support for carers, all relevant to the work undertaken in the 25 DS, including the need to:

- Give more attention to carers' needs at first contact (p6, p44).

- Follow up and monitor the outcomes for carers re-directed to other organisations (p44).

- *'Improve the range of services (councils) offer to all carers, increase the number who take breaks, and improve monitoring to ensure that their services are meeting carers' needs and leading to positive outcomes'* (p54).

The CQC report also noted that only a quarter (of 42 councils assessed) were strong in getting service users and carers involved (p34); that there was still a need for improvement in the area of 'carers' rights and needs' (p46); that in relation to a specific service (support following stroke) one third of areas lacked peer support arrangements such as befriending schemes and carer support groups (p51); and that support for carers was 'a strength' in only 54 councils assessed, with one third needing to improve (p54).

These (and other) gaps and weaknesses in carer support are among the aspects of the health and social care system which the 25 DS addressed with the additional resources available to them through the DS programme. Their experiences of doing this are therefore of particular relevance to how agencies across the English health and social care system can improve their support for carers in the future.

As a King's Fund report on 'Social care funding and the NHS' noted in 2011, public spending decisions on adult social care since 2010 have included *'a real-terms increase in grant funding for social care of around £875 million a year on average over the next four years'* as well as £1 billion of extra funding for the NHS to invest in measures that *'support social care and benefit health'* (Humphries, 2011:6). However the King's Fund report also pointed out that these investments were accompanied by a *'tough spending settlement for local government'*, and that adult social care funding is not 'ring-fenced'. It explained that the backdrop to these recent investment decisions includes over 15 years of real-terms growth in adult social care expenditure, much of it *'absorbed by demographic pressures'*, and evidence that 'productivity' in the NHS and (especially) in adult social care has been falling (Humphries, 2011:1-2). This means that in coming years there needs to be a real emphasis on improving services that are cost-effective: that is, capable of improving outcomes for carers and service users, but also of keeping within tight budgets and of 'investing to save', on costs elsewhere, wherever possible.

In November 2010, the Coalition government, advised by the Standing Commission on Carers, and drawing on evidence available to it from the CQC as the sector regulator and from more than 750 responses to a consultation exercise, set out four priority areas in relation to carers in its 2010 Carers' Strategy (HMG, 2010a). The priority areas were:

- Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages.

- Enabling those with caring responsibilities to fulfil their educational and employment potential.

- Personalised support both for carers and those they support, enabling them to have a family and community life.

- Supporting carers to remain mentally and physically well.   (HMG, 2010a:6)

This emphasis in the 2010 Carers' Strategy on carer identification and involvement, on the need for personalised support which maintains carers' health and well-being and on carers' ability to participate in everyday life reinforced commitments to carers set out by the previous government (in the 2008 National Carers' Strategy). In a ministerial foreword, the Coalition government emphasised that its *'vision'* for adult social care involved *'developing a more personalised, preventative service, delivered in partnership with the NHS and voluntary and user-led groups'*. It also noted that *'supporting carers' well-being is in all our interests'* and that *'the role of carers, and government's support for carers, in developing these kinds of services is … more vital than ever'* (HMG, 2010a: 6).

At around the same time the government also published *A Vision for Social Care: capable communities and active citizens*, setting out seven principles for a 'modern' system of social care. These were:

- *Prevention:* empowered people and strong communities will work together to maintain independence.

- *Personalisation:* individuals not institutions take control of their care.

- *Partnership:* care and support delivered in a partnership between individuals, communities, the voluntary and private sectors, the NHS and councils.

- *Plurality:* the variety of people's needs is met by diverse service provision.

- *Protection:* there are sensible safeguards against the risk of abuse or neglect.

- *Productivity:* greater local accountability will drive improvements and innovation to deliver higher productivity and high quality care and support services.

- *People:* We need the whole workforce, including care workers, nurses, occupational therapists, physiotherapists and social workers, alongside carers and the people who use services, to lead the changes.   (DH, 2010a:8)

As shown already in earlier chapters of this report, the innovations and service developments demonstrated by the 25 partnerships in the DS programme included a strong focus on most, if not all, of these principles. The emphasis on prevention, personalisation, partnership, plurality and people was characteristic of all three types of DS: Breaks, Health Checks and Better NHS Support. In most of the sites, staff (and the Expert Advisers who guided and supported them) felt that the work they had done with the additional resources available had produced good quality services and good outcomes for carers. The national and local evaluation studies examining their work bear this out, particularly in terms of carer feedback and response. Sites had more difficulty, however, in demonstrating improvements in productivity (a concept which not all health and social care staff will have been trained to focus upon, but which is changing, especially within the NHS as the QIPP transformational programme is introduced[67]). This may explain why their monitoring systems, measurement of costs and outcomes, and recording of hidden costs (as well as budgeted expenditure), was often inadequate or weak, and why many struggled, as they themselves acknowledged, with these aspects (see Chapter 6).

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[67] QIPP (Quality, Innovation, Productivity and Prevention) is *'a large scale transformational programme for the NHS involving NHS staff, clinicians, patients and the voluntary sector, designed to 'improve the quality of care the NHS delivers whilst making up to £20 billion of efficiency savings by 2014-15 which will be re-invested in frontline care.'* (DH, 2011: http://www.dh.gov.uk/en/Healthcare/ Qualityandproductivity/QIPP/index.htm.)

To support its ambitions for improving carer support, the government also made additional funds available (£400 million over the four years 2011-15) in its baseline allocations to PCTs (and thus to the GP consortia expected to replace PCTs in the future), announcing this in the 2010 Carers' Strategy. The NHS Operating Framework for 2011/12 additionally advised that:

> *PCTs should pool budgets with local authorities to provide carers' breaks, as far as possible, via direct payments or personal health budgets. For 2011/12, PCTs should agree policies, plans and budgets to support carers with local authorities and local carers' organisations.*   *(DH, 2010e)*

Contractual arrangements affecting GPs (introduced in 2004) already included a QOF indicator awarding points to practices with a protocol in place for identifying carers and referring them for assessment (PRTC/RCGP, 2011)[68].

A further development relevant to the landscape for health and social care in the future is the Law Commission's work on adult social care, which began in 2008 and resulted in a final report, published in May 2011. This made recommendations for the reform of adult social care with regard to the legal framework needed, the statutory principles associated with it, and issues of assessment, eligibility and responsibility for service provision. For England, the Law Commission recommendations relevant to this report are set out in Box 7.1.

The recommendations of the Law Commission, if accepted, would place the responsibility for Carers' Assessments (and for ensuring services were available to meet carers' assessed needs) firmly on the shoulders of local authorities. The experiences of all 25 DS included collaborative working across the health, social care and voluntary sectors, and in considering how their work may inform future developments in adult social care, it will be important to bear in mind the need for flexibility and multi-agency engagement as well as for clear lines of responsibility and accountability. The Law Commission's proposals, outlined in Box 7.1, received broad support from the Commission on Funding of Care and Support, chaired by Andrew Dilnot, which reported in July 2011 and made major recommendations about the funding of adult social care[69].

The Commission also looked at the question of how the adult social care system could be 'made to work for people', noting the importance of the *'contribution of carers'*. It called for *'a new information and advice strategy … with local government taking responsibility for signposting people to reliable services and advice'* (p42), through a strategy co-produced *'with third-sector organisations and other interested parties'* to deliver *'better provision of basic, factual information at the national level'* (p43). The Commission set out the case for a new social care statute, emphasising that local authorities should *'offer specific support to carers, including signposting to third-sector organisations where appropriate'* (p44), with care assessments both 'transparent' and 'portable'.

On the contribution carers make to the adult social care system and to the economy, the Commission on Funding of Care and Support focused on three issues, all *'raised consistently'* in its consultations with carers and carers' organisations: *'improved carers' assessments; better information and advice, and support to work'* (p51). Carers, it argued, should be *'properly and fairly assessed',* and *'better supported by clear access to services with the aim of ensuring that their care is manageable and sustainable'* (p52). It concluded (p54): *'better support for carers must be a key component of an improved information and advice service. In particular we think GPs should ensure that they are mindful of the effects that caring can have on someone's health and seek to ensure appropriate support is in place'.*

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[68] The QOF (Quality and Outcomes Framework) 'rewards GP practices for how well they care for patients' http://www.dh.gov.uk/en/Healthcare/Primarycare/PMC/Quality/OutcomesFramework/index.htm.

[69] It found current funding arrangements 'not fit for purpose' (despite the £14.5 billion spent annually on adult social care in England) and in need of 'urgent reform' (Commission on the Funding of Care and Support, 2011:11). Funding issues, which are not the focus of this report, are not considered here.

**Box 7.1 Recommendations of the Law Commission
relevant to carer support and services**

A *'unified adult social care statute'* setting out *'the core duties and powers of local social services authorities'*, and supported by *'regulations'* (issued by the Secretary of State) and a *'code of practice'* to guide local authorities is needed.

The statute should establish that *'the overarching purpose of adult social care is to promote or contribute to the well-being of the individual'*, with decisions based on individual circumstances and individuals involved in *'assessments, planning, developing and reviewing their care and support'*.

'Universal' and *'targeted'* adult social care services are needed. *'Information, advice and assistance'* should be available to all; targeted support should follow a community care assessment, *'based on a single, clear duty to assess a person'* in consultation *'with the individual and their carer'*.

To encourage *'joined up assessments'*, local authorities should be able to *'carry out a community care assessment at the same time as any other assessment'*. Assessment of need and the application of eligibility criteria should be *'the sole means by which a person's eligibility for community care services is determined'*.

Undertaking a carer's assessment should involve a *'single and standalone duty'*, requiring only that *'the cared-for person is someone for whom the local authority has a power to provide services'*. It should arise *'even if the cared-for person has refused an assessment or is not eligible for services'*, and should not require a carer *'to be providing a substantial amount of care on a regular basis'*.

Assessment should focus on *'the carer's ability to provide and to continue to provide care … and take into account whether the carer wishes to work or undertake education, training or any leisure activity'*.

Provision of services following assessment should be based on an *'eligibility framework for carers' services'*, with local authorities required to meet the eligible needs of carers 'by providing services to the cared-for person or to the carer and guided by *'a list of general services and outcomes'*.

Outcomes should focus on *'health and emotional well-being; protection from harm; education, training and recreation; the contribution made to society; securing rights and entitlements'*.

The statute should place a duty on local authorities to produce a written care and support plan (to be regularly reviewed) summarising the needs and outcomes to be achieved, any available personal budget, and a summary of services/direct payments to be provided.

Source: Law Commission, 2011.

This developing, and still in some respects undecided, policy context for social care (and thus the context for supporting carers in the future) informs the evidence-based conclusions and recommendations made in this chapter. These draw on the evidence presented in Chapters 2 to 6 of the report and offer guidance on how learning from the DS can help build carers' services in the future.

7.3   Evidence-based conclusions

This section presents evidence-based conclusions drawn from the main findings of the study, as presented in earlier chapters. These focus on the learning and impact of the DS programme and inform the policy recommendations which follow.

Impact on carers

(i) The DS were particularly effective in reaching some carers - carers in ethnic minority groups, carers of people with some health conditions, and carers likely to need support in maintaining their own health and well-being. They made contact with many carers with substantial and long-term caring roles, in some cases working successfully to engage carers of people with dementia, mental ill-health, long-term / terminal illness, a learning disability or substance misuse problems. Most of the carers supported were women and older carers. *Conclusion: The DS adopted approaches which worked well in targeting some of the neediest carers. Future services need to take care to ensure that the needs of male carers and of younger carers are not neglected.*

(ii) The carers supported by the sites were strongly positive about the services and other help they received, making very few negative comments. The vast majority said they would recommend the service they had received to other carers. *Conclusion: Most carers supported by the DS felt they benefitted from the kinds of services offered, finding them a suitable way of meeting some of their otherwise unmet needs.*

(iii) In the Breaks sites, 80% of carers supported were people who had not previously been able to take a break from caring for more than a few hours. In the NHS Support sites, particularly those identifying carers in hospitals, many carers had never received any support to help them in their caring role before, or were new to caring. Most carers who accessed the Health Checks sites had seen a healthcare professional about their own health in the past six months, but their appreciation of the new emphasis on well-being, and the more holistic approach taken (with time to feel listened to and supported) came through strongly in the evidence in many sites. *Conclusion: Support of the type offered in the Breaks and NHS support sites filled an important gap in services for carers, and services of this kind should be prioritised. The well-being support offered in Health Checks sites was a new form of support for most who received it, filling a previously unmet need, and should also be developed.*

(iv) Accessing the DS breaks services enabled some carers to have more of a 'life of their own' and to build confidence; some carers also reported changes in their behaviour and activities which were beneficial for their own well-being or health. A third started a new leisure activity, and some reported improvements in their communications with professionals and in their knowledge of carers' entitlements. Carers who did not receive a break were more likely than those who did get such support to show deterioration in well-being scores. *Conclusion: Flexible and personalised breaks support is life-enhancing for many carers. It has the potential to prevent carer burn-out / health deterioration and to help sustain their caring role.*

(v) Although some carers were surprised that 'safety in being a carer' was not covered in all the health checks services, the health checks offered had a positive impact on a large minority of those supported. Four months later a quarter said that both how they looked after their health and the amount of exercise they took had improved. Most had been signposted to additional services. A few said this had not been helpful, suggesting care needs to be taken in referring carers to other support that it is both appropriate and followed up. *Conclusion: Health and well-being checks lead to sustained self-care and healthier behaviour for some carers. Arrangements for signposting carers to support need to be carefully monitored for their suitability and effectiveness in each individual case.*

Innovation and effective practice

(i) In implementing their plans, the DS delivered support for carers in new settings, via new or extended local partnerships. Many developed new delivery approaches or other new ways of working. Most sites developed at least some new services which were innovative, and many made significant changes to existing provision which they considered made a positive difference to carers' health and well-being. *Conclusion: Staff in the NHS, local authorities and voluntary sector organisations, working together, developed a wide range of creative and sometimes innovative approaches which worked flexibly for carers and offered them personalised support.*

(ii) Almost all sites worked with partners across the health, social care and voluntary sectors, and some also engaged with other agencies, including some private sector organisations. The role of the partner agencies varied by site type and the specific activities offered. *Conclusion: Standardisation and uniformity is not appropriate in developing and delivering carers' services, but flexibility and responsiveness to local circumstances can work well. The allocation of leading and supporting roles within partnerships should reflect local priorities, needs and circumstances.*

(iii) The breaks provision offered in the DS included: specialised short-term respite for carers of people with dementia / mental ill-health; imaginative use of alternative care in the home; and an extremely flexible approach to the delivery of personalised breaks (based on carers' own needs). Some of the options offered were inexpensive. *Conclusion: Some carers derive significant benefit from relatively low-cost support at appropriate points.*

(iv)The health checks services were offered in various different ways, through both combined and separate physical health examinations and health and well-being checks. Some sites experimented (with some success) with delivering these using staff who were not clinically qualified and / or with staff based in voluntary organisations. *Conclusion: Well-being support was offered in a variety of settings, in different ways: some options valued by carers do not rely exclusively on input from fully qualified clinical staff.*

(v) NHS support services offered new ways of supporting carers in both hospital and primary care settings. They included befriending and peer support activities, awareness training for staff, and improving information, documentation and access to Carer's Assessments. *Conclusion: Some success was achieved through establishing 'carers' champion' roles in GP practices, linked to other partner agencies and support. In hospitals, successful practices included ward-based initiatives, co-ordinated and led by voluntary sector agencies, which involved nurses, doctors and health care assistants and made services and support available to carers in the hospital setting.*

(vi) All sites focussed on making support accessible to carers. Most Breaks sites explored new approaches such as on-line booking systems and ways of providing a break without requiring carers to complete a Carer's Assessment. Health Checks sites offered the checks in a variety of venues including carers' own homes and local community centres. The NHS support sites offered new ways of delivering Carer's Assessments and helped carers access a wide variety of other support. Almost all sites found demand for services was difficult to predict and that they needed to be extremely flexible in adjusting the services offered to meet carers' needs in a timely and appropriate manner. *Conclusion: Carers access support via different routes, according to their own caring circumstances. Services need to be accessible at key points in the carer's journey, especially when caring first arises, at points of change or stress in their caring situation and on a regular basis when caring is long-term and intensive.*

Partnerships and multi-agency approaches

(i) In developing their new services, most DS found there was some impact on staff roles, multi-agency partnerships and working relationships. The changes they introduced appeared to have a positive effect on system responsiveness and care co-ordination, with particular benefits in terms of the quality and accessibility of carers' services. *Conclusion: Multi-agency support for carers can be developed without an unduly disruptive effect on the workloads of staff in the health and social care system. Organisations should expect initial setting-up of new arrangements to be time-consuming, however, and a flexible approach to job content and professional roles may sometimes be required of some staff.*

(ii) Impacts on staff included improved teamwork, greater carer awareness, new activities (especially to engage with carers not previously in touch with support services), and developing new skills. Some staff reported an increase in workload, with staff in the voluntary sector organisations involved in outreach activities particularly affected. *Conclusion: In developing carer support, voluntary sector organisations play a key role and may provide expertise not available elsewhere. In planning service implementation, care should be taken to avoid over-burdening voluntary sector staff and to ensure that their roles and activities are adequately resourced.*

(iii) Staff experiences of the different approaches taken in the DS included: working in carers' homes; requiring additional training; and working imaginatively to overcome resistance among some colleagues to engage with the new services. Health and social care professionals nevertheless reported relatively few problems in integrating the new DS activities into their existing roles; this included staff in NHS roles in both primary care and hospital services, as well as staff in local authorities and voluntary sector organisations. *Conclusion: Some of the carer support offered in the DS required additional training for staff in some or all partner organisations. Carer awareness training is likely to be particularly necessary in NHS organisations, and voluntary sector organisation staff may need additional training for specialist roles, such as delivering well-being checks to carers.*

(iv) Most sites developed partnerships which included voluntary sector organisations, NHS organisations and local authorities. Breaks sites were local authority led, NHS Support sites tended to be NHS-led, and leadership arrangements in the Health Checks sites varied. Most partnerships were formally established with clarity about roles and responsibilities and governance which included carer input. Some found it beneficial to develop additional informal networks, particularly to support outreach to additional carer groups. *Conclusion: Organisations in all segments of the health and social care system should be encouraged to take on leading roles, where appropriate, to deliver carer support. It should not be assumed that local authorities need to lead all developments, although involvement of relevant local authority services is likely to be beneficial for most carer support projects.*

(v) Difficulties encountered in the DS partnerships included: collaborating in the context of different organisational procedures and / or access to resources; a disappointing level of commitment among some partners; differential engagement among GPs; and some concerns in local voluntary organisations that carers registered with them might be drawn away, possibly undermining their future capacity to attract funding. *Conclusion: Organisations bring different practices and systems to partnerships, and how to integrate these requires careful consideration when new developments are planned. Special approaches may be needed to encourage GPs to engage with carer support arrangements. The previous work of local carers' organisations in building local intelligence on carers and their support needs should be valued and discussed when projects are designed.*

(vi) Partnership outcomes included improved: carer support procedures; monitoring systems; communication networks (across the health and social care system); and more effective and comprehensive carer awareness training for staff. *Conclusion: The DS programme leaves a legacy of documentation and tested processes on which future development of support for carers can build.*

Identifying, engaging and involving carers

(i) Most sites identified several different target groups in their initial bids for DS funding, with the Health Checks sites targeting a particularly wide range of carers. Target groups were varied and most sites identified several, for example including ethnic minority carers, carers of people with dementia, carers of people with mental ill-health and young carers. *Conclusion: Careful consideration of local needs and circumstances can help multi-agency partnerships to target carer support towards those in greatest need. The DS programme provides many examples of effective ways of targeting specific groups of carers.*

(ii) The sites each selected specific local priorities for engaging with carers, both in terms of the numbers they aimed to support and the characteristics of the carers they decided to target. Their experiences of reaching the groups identified and anticipated numbers of carers varied considerably. Five sites met or exceeded their overall targets for carer numbers and five others almost reached the figures they initially set; they included all three types of DS, with NHS support sites especially successful in this respect. *Conclusion: There is considerable scope for extending and improving carer support through NHS-led initiatives developed in partnership with relevant agencies.*

(iii) The survey and monitoring data showed that the carers supported by the DS were predominantly older, female carers, and that some sites, particularly those offering health checks, engaged very successfully with carers from ethnic minority communities. Compared with the national profile of carers, carers of people experiencing dementia, mental ill-health, long-term/terminal illness, learning disabilities and substance misuse problems were also well represented among carers supported by the DS. *Conclusion: Targeting carers in line with local priorities works well, but as other evidence indicated, male and younger carers may be missed if not specifically identified.*

(iv) Success in engaging with carers, especially those in target groups, was affected by the engagement initiatives sites selected. Although some sites faced challenges in engaging GPs and other healthcare professionals, partnerships with NHS organisations appeared to be especially important in reaching carers. This was particularly evident in the NHS support sites, but also worked well in some Health Checks sites. Partnership working with organisations beyond the health and social care sector played an important role in helping some sites engage with carers. In the Breaks sites, innovative approaches to reaching young carers, through partnerships with schools, colleges, youth centres and universities, worked particularly well. Many sites worked successfully with voluntary sector organisations (including carers' centres) and engaged them to undertake outreach work. Many Breaks sites found this approach effective in engaging with ethnic minority carers. Sites more successful at identifying and engaging with large numbers of carers, and in meeting their planned targets, often used a combination of different techniques and strategies: adopting tailored initiatives for targeting specific groups and ensuring that these efforts were on-going rather than one-off initiatives. *Conclusion: Effective support for carers requires strong multi-agency partnerships supported by additional networks, within and beyond the health and social care system, to support carer identification, engagement and involvement.*

(v) Most sites developed a range of marketing strategies to raise awareness of the DS services, with websites used in some, with mixed results, as a means of improving accessibility. Many DS staff felt gaining carers' trust through face-to-face contact was the best way of engaging with them. Comparison of the approaches adopted by the different sites showed no identifiable relationship between higher spending on marketing and success in engaging with larger numbers of carers. DS staff often reported that it was best to avoid the term 'carer' in marketing materials and when attempting to engage carers new to accessing support. *Conclusion: In recruiting carers, agencies rely heavily on word-of-mouth and face-to-face contact and many lack the capacity and expertise to mount really effective local marketing campaigns.*

(vi) All sites attempted to involve carers in designing the DS services, and nine engaged carers in delivering the support they offered. There was some evidence that a high degree of carer involvement was associated with success in engaging carers. Many DS staff felt involving carers in the design, delivery and evaluation of the site activities was a successful aspect of the DS programme, pointing out that carers often raised issues professionals had not considered, with a range of benefits for the carers supported. Some intended to continue with carer involvement in service planning, describing it as a 'legacy' of the programme. *Conclusion: Good practice in involving carers means including them in project planning from the start, ensuring they have adequate support and training in the roles they play, drawing a diverse range of carers into projects, and being attentive to, and flexible about, challenges in involving them. Carers may face difficulties in participating regularly in relevant meetings and processes, and this needs to be recognised and accommodated.*

Costs and benefits in the health and social care system

The DS programme was designed not only to deliver better support and services to carers but also to improve understanding of which kinds of delivery arrangements and forms of carer support are sustainable and cost effective. This required a focus on the costs and benefits of direct provision and an assessment of the potential for cost savings in the wider health and social care system.

(i) Both total site costs and the cost per individual carer supported varied substantially between sites (both within and between the three different types of site, Breaks, Health Checks and NHS Support). All three types of support showed some potential to produce cost savings for one or more of the agencies providing the service as well as in the health and social care sector more widely, although quantifying and specifying these proved very challenging. *Conclusion: Variable prior experience, different targets and complex configurations of support made identifying which DS sites offered best value for money impossible. As some of the service and support options developed are rolled out more widely, opportunities will arise to compare similar projects and identify efficiencies in delivering them.*

(ii) The evaluation evidence showed that the support developed had the potential to save costs by: preventing some hospital and residential care admissions (of those cared for); supporting carers to sustain their caring role for longer (avoiding home care or residential care costs); identifying carers' physical and/or mental health problems earlier (enabling them to be treated more cheaply or effectively and supporting them to access healthcare at appropriate times); improving carer health and well-being (potentially avoiding or delaying carers becoming users of care support themselves); better partnership working (avoiding duplication and inefficiencies in service development and delivery); efficiency savings in GP practices (including fewer appointments missed); supporting carers to return to, or remain in, paid work (avoiding costs in the benefits system); and establishing very low cost informal local networks of support for carers (as a cheaper alternative to formal support). Many sites continued to offer all or part of the carers' support services provided within the DS programme after the DS funding period ended, suggesting that local agencies recognise their value. *Conclusion: The wide range of ways in which cost savings may potentially be made, given the relatively modest costs of providing carer support, suggest that continuing to expand support for carers, especially when caring begins, for those with intensive or long-term caring roles, and when carers experience strain, is likely to be a financially sustainable approach. While some sites made some progress in calculating costs savings, it may never be possible to put an accurate figure on the precise costs saved. The DS programme showed positive health and well-being outcomes for substantial numbers of carers and very positive carer responses to relatively low-cost support.*

(iii) Both the local evaluators and the national evaluation team encountered great difficulty in identifying mechanisms for calculating the cost effectiveness of carer support, as the impact of the interventions could not be isolated from other factors in a continuously changing health and social care environment. *Conclusion: Further work on building suitable tools is needed if the cost-effectiveness of carer support*

is to be measurable. The DS programme or similar programmes in which different sites are tasked with innovation and experimentation are not ideal vehicles for measuring costs and benefits. More controlled interventions, over longer time spans, ideally with comparator groups, would provide a more suitable environment for this type of measurement.

7.4   Policy recommendations

Publication of this report in autumn 2011 coincides with the government's engagement exercise on the Future of Care and Support, providing an important opportunity for learning from the DS programme to be applied as new arrangements are put in place after 2012, when the Secretary of State for Health plans to publish a White Paper on Care and Support.

The policy recommendations which follow are consistent with the seven principles set out by government in the 2010 Carers Strategy (described in section 7.2).

1. *In all localities, efforts to bring local authorities, NHS organisations and voluntary sector organisations together* to develop and deliver effective support for carers, in partnership, *should be strengthened*. Partnerships, which might operate as, through or in consultation with health and wellbeing boards, and may build upon or further develop existing local partnership arrangements, should agree future-oriented local strategies and budgets for carer support which enable them to plan, develop and implement suitable services. This approach is consistent with guidance already issued to PCTs by government in 2010 (section 7.2).

2. *Local carer support partnerships should involve a diverse range of carers in service development*, offering them suitable training, and should work with them to review carers' needs, identify local priorities for developing carer support, and select the leading and supporting agencies needed to deliver different types of carers' services.

3. In delivering support to a wide range of carers and reaching carers not already in touch with services, *local partnerships should work flexibly*, and sometimes on an *ad hoc* basis, to engage carers in specific target groups. To establish and sustain support for some groups of carers, flexible networks, where appropriate involving agencies outside the health and social care system which are trusted by carers or which work with people who are carers, may be required.

4. No single type of carer support is best or offers a panacea for all carers or all caring situations. *Effective carer support at the local level should always include a varied portfolio of carer support services*, which can be adapted to meet individual needs. Flexible and personalised services need not be expensive, but must be available to carers in a timely manner and capable of responding rapidly to carers' needs, which can arise unpredictably or unexpectedly.

5. *Portfolios of carer support need to be agreed locally* between local authorities, NHS organisations, voluntary sector organisations and other organisations where appropriate. Carers need support with: health problems and stress; information on how to access suitable support, services, equipment and home adaptations for those they care for; income maintenance and pensions protection during and after caring; self-care, healthy lifestyles and maintaining a life outside of caring; access to education, training, work and leisure; emergency planning and how to access occasional or regular breaks from their caring role.

6. *Hospitals should routinely provide mechanisms to identify and support new carers*, centring their efforts on wards where patients have received a new diagnosis or are due to be discharged and on out-patient clinics where patients are likely to be accompanied by those who care for them. Timely and co-ordinated support for new carers and carers with changing care responsibilities, linked to follow-up services, should be available in every acute hospital and advertised in all out-patient clinics.

7. All GP practices have contact with carers, even if this is not always recognised locally. *Every GP practice should be encouraged to identify a lead worker for carer support*, who can assist in carer identification, help in referring carers to suitable local services, and ensure carers' access to health appointments and treatments is not impeded by their caring circumstances. These workers may require carer awareness and carer support training. The action guide 'Supporting Carers', for GPs and their teams, published by the PRTC and the RCGP in October 2011, provides detailed suggestions for practical ways of taking this forward.

8. *All staff who interact with carers*, in hospitals, GP practices, local authorities and in the voluntary sector *should be trained to consider how caring responsibilities can impact on a carer's health and well-being* and equipped to advise on how a carer can access a health and / or well-being check. Checklists, protocols and guidance for professionals and support workers which has been developed and tested in the DS programme should be made widely available in the health and social care system, and all relevant workers should be trained to look for signs of stress or of deteriorating health among carers and to offer guidance on suitable support. Local partnerships should consider resourcing local voluntary sector organisations to deliver well-being checks for carers.

9. Many workers in the health and social care system, particularly (but not only) in the NHS, could provide more effective support to carers if they had benefitted from carer awareness training. *All relevant organisations should regularly offer carer awareness training to their staff.* Training need not be costly and for some staff groups, on-line or web-based training modules may be an inexpensive and appropriate option.

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About CIRCLE

CIRCLE *(Centre for International Research on Care, Labour and Equalities)* is a research centre of the University of Leeds, based in the School of Sociology and Social Policy. CIRCLE is directed by Professor Sue Yeandle.

For all enquiries contact:

CIRCLE
School of Sociology and Social Policy
University of Leeds
Leeds LS2 9JT
UK

Tel: +44 (0)113 343 5003
Email: CIRCLEadmin@leeds.ac.uk
Web: www.sociology.leeds.ac.uk/circle