New Approaches to Supporting Carers' Health and Well-being: Evidence from the National Carers Strategy Demonstrator Sites Programme

Appendices

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Appendix A Research Instruments

Appendix A.1 Evaluation methodology: further details

This appendix presents more detailed information about the evaluation methodology used by the national evaluation team, a broad overview of which is provided in Chapter 1.

Research questions

The evaluation objectives (specified in Chapter 1) generated a set of primary research questions relevant to all three intervention types (Breaks, Health Checks, NHS support).

- 1. What new policies and delivery processes are being put in place, and what types of benefit do they produce for carers and those they care for?
- 2. Where comparison is possible / appropriate, what is the relative effectiveness of the different policy innovations, and what are their comparative costs?
- 3. How far do the different policy innovations offer scope for future cost savings in the health and social care system via improved health outcomes for carers and more sustainable caring arrangements?
- 4. What are the implications of the different models of service delivery for service providers and other stakeholders? How do they contribute to the improvement of system responsiveness and care co-ordination?
- 5. How do carers come into contact with improved services / support and what type of support / service do they receive?

Further to the primary set of research questions outlined in Chapter 1, a detailed set of research questions were also agreed for each of the three types of Demonstrator Sites.

For Breaks sites

- 1. By offering different types of breaks, have providers succeeded in *personalising* support to meet carers' individual circumstances, achieving a good fit between the design of the break and the carer's needs (length, duration, frequency, etc.)?
- 2. Have the breaks innovations improved carers' *access* to break(s) (via better information, reduced waiting times, altered eligibility, assessment, charging, etc.)?
- 3. How many carers, with which characteristics, have been supported in accessing a *wider range and better quality* of breaks (with more flexibility, a choice of location / break type, continuity of personnel, reliability, etc.)?
- 4. What are the perceptions of *different groups of carers* about how the interventions have improved their own health and well-being, helped them to better manage their caring situation, enabled them to sustain employment, training, or education alongside their caring role, or benefitted the person they care for?
- 5. What are *professionals'* and *practitioners' perspectives* on the relative benefits of the interventions for the health of different groups of carers, the well-being of those cared for, the delivery of more responsive and flexible services, the success of the different types of breaks in reducing admissions to residential care, preventing the breakdown of caring relationships?

For Health Checks sites

1. How successful are the different modes of offering health checks to carers in terms of take-up, early detection of health conditions / risks, etc?

2. Which groups of carers respond most positively / negatively to the offer of a check, and why?

3. What were carers' expectations of the health checks; were these met (areas of health investigated; how check was conducted; outcomes, follow-up, advice received); and what benefits did carers associate with the check?

4. What kinds of manageable health risks were identified via the checks, and what is the potential for sustaining caring relationships for longer, and avoiding future health costs, through this approach?

5. Do healthcare professionals and independent sector agencies view the different types of health checks as supporting or disrupting other local preventative / health promotion schemes?

For NHS Support sites

- 1. How are carers identified, by whom, as suitable for enhanced NHS support, and what type of support is given, at what stage, to which carers?
- 2. Which professionals view the enhanced support most positively / negatively, and how does delivering it impact on the workloads of, and working relationships between, different groups of health and social care professionals and relevant independent sector agencies?
- 3. In what circumstances, if any, was the enhanced support associated with the earlier hospital discharge or delayed / avoided admission to residential / hospital care of the person cared for?
- 4. Which groups of carers were enabled to better manage their caring situation / continue caring (in combination with which other activities) through the enhanced NHS support?
- 5. Did the enhanced support succeed in engaging with self-funders of social care, and with what outcomes?

Study implementation

In order to ensure the national evaluation proceeded as efficiently as possible, regular contact was maintained with the Department of Health throughout to discuss developments, progress and adjustments to the study methodology. The evaluation team also liaised with the DH over ethical approval issues and the research instruments used. An interim evaluation report was submitted to the DH in September 2010. Following preparatory work and a period of familiarisation with the Demonstrator Sites programme, collection of data from the 25 DS took place in 2010 and early 2011.

Research ethics

Throughout the study period, the evaluation team was guided in its work by the DH Research Governance Framework for Health and Social Care. In autumn 2009, the study was judged to require full NHS NREC approval (as a research study). This was unexpected given that the study has been commissioned as a policy evaluation, and led to an extremely complex range of ethical approval and research access processes (fully described

elsewhere¹) during autumn 2009 and spring 2010. As a result of this, different elements of the study were implemented at slightly different times in each of the 25 sites, as and when the site-specific approval processes for each were complete.

Monitoring of DS activities and expenditure

The national evaluation used a variety of research tools to monitor activity in the DS sites, including Baseline Data statements, Individual Carer Records (ICRs) and Quarterly Reporting Templates (QRTs).

The national evaluation team asked sites to complete an ICR with every (consenting) carer who accessed their services, in order to collect basic demographic information about each carer accessing DS services². This allowed the national evaluation team to compare the characteristics of carers accessing the DS service with existing profiles of carers (such as those based on 2001 Census data) to assess if carers benefiting from the DS programme were representative of all carers (Chapter 5). The national evaluation team anticipated that sites would manage to gain consent for completion of an ICR from the majority of carers accessing their services, but this was not the case. A total of 5,050 ICRs were received from all sites from the 18,653 carers receiving DS services (Table 5.1). This arose partly because some carers received support before ICRs could be distributed because full ethical approval had not been granted locally. The percentage of carers for whom ICRs were returned was particularly low in NHS Support sites (where only 8% of carers who engaged these sites' activities completed an ICR)³.

QRTs were sent to sites for completion at six points, to be completed with respect to the preceding three months (quarter). Guidance for completion of QRTs was issued to sites (Appendix A.3). All QRTs were received from the majority of sites, although deadlines were not always met and some sites only submitted these documents after repeated reminders from the research team.

Documentary analysis

Documentary analysis was an ongoing activity used to gather information to: map the range, type, variety, scale and costs of DS service provision; identify delivery relationships / partnerships; and capture local objectives, design features and operational decision making. Documents were provided by sites throughout the delivery period and were electronically logged, read and summarised. Information relating to the evaluation research questions was recorded in a thematic template for each site. Documents submitted by sites for analysis included marketing materials, local evaluation plans and data, delivery documents and budgetary information. The number of documents submitted by each site varied from ten to 117 (Table A.1).

¹ A full account of issues arising from ethical approval arrangements was submitted in response to the Academy of the Medical Sciences' call for evidence on the operation of research ethics approval processes in 2010. A copy of this submission was shared with the DH and the DS via the DS website (in an appendix to the interim report of the national evaluation of the Demonstrator Sites programme) in September 2010.

² ICRs were designed to be completed on paper while the carer was present. Sites were asked to upload ICR data to the national evaluation team via a secure website.

³ To gather data on the characteristics of carers, in some sites (where there were delays with ethical approval procedures) access was given to anonymised ICR data, with postcodes and date of birth removed. This affected the data analysis as these ICRs could not be matched to survey responses.

Table A.1 Th	e national ev	aluation of	the DS program	nme: site p	articipation a	nd responses rec	eived		
	Carers engaging with site activities number	ICRs returned		Carer Survey: Wave 1 Questionnaires					
Site		number	as % of carers engaging with site activities	Sent to site number	Returned number	Questionnaires returned %	Documents submitted to website number	Documents submitted to NET number	Local evaluation report returned ³
Bath and NE Somerset	438	240	42	285	119	42	11	17	Y
Bristol ¹	756	292	39	90	20	22	10	29	Y
Derby ¹	915	66	7	185	29	16	18	40	Y
East Sussex ^{1, 2}	605	452	75	165	7 ²	N/A	17	34	Y
Hertfordshire ¹	689	54	8	115	38	33	97	117	Y
Lewisham	100	30	30	75	19	25	9	18	Y
Liverpool	266	242	91	75	28	37	16	46	Draft
Nottinghamshire	708	73	10	220	47	21	5	35	Y
Suffolk ^{1, 2}	509	248	49	135	3 ²	N/A	55	80	Y
Sunderland ¹	389	287	74	220	26	12	13	28	Y
Torbay ¹	255	74	29	100	15	15	9	27	Draft
Warwickshire ¹	25	3	12	25	2	8	25	54	Y
Carers Breaks ALL	5,655	2,061	36	1,690	353	21	285	525	
Camden ¹	268	192	72	280	61	22	44	71	Y
Devon	2,924	1,158	40	520	229	44	38	54	Y
Northumberland ¹	457	457	100	270	75	28	1	20	Y
Redbridge ¹	600	310	52	100	57	57	20	50	Y
Tower Hamlets	605	218	38	210	31	15	1	10	Draft
Trafford ¹	587	45	8	175	0	0	21	39	Y
Health Checks ALL	5,441	2,380	44	1,555	453	29	125	244	
Bolton	785	123	16	160	47	29	22	32	Y
Halton and St Helens ¹	3,510	18	1	720	64	9	32	54	Y
Hastings and Rother ¹	1,060	36	3	120	18	15	35	70	Y
Northamptonshire ¹	554	52	9	65	18	28	4	66	Incomplete
South West Essex ¹	450	63	14	100	18	18	4	17	Y
Swindon	618	47	8	50	26	52	116	116	Y
West Kent	580	270	47	80	11	14	81	81	Y
NHS Support ALL	7,557	609	8	1,295	202	16	294	436	
TOTAL	18, 653	5,050	11	4,540	1,008	22	704	1205	

Sources: ICRs, QRTs.

Notes:

¹Denotes case study site ² In addition to the wave one questionnaire, the East Sussex and Suffolk sites both used a version of the carer questionnaire which combined the questions asked in waves one and two of the 'standard' Carers Breaks Surveys. This elicited 14 responses from Suffolk and 79 from East Sussex which are not shown in the table above but were used in the analysis of the data. ³ Local evaluation reports returned to the national evaluation team by deadline agreed with site. Some reports were marked as 'draft' or 'incomplete' by sites (as indicated in the table).

Case studies

As outlined in Chapter 1, the purpose of using case studies was to gather detailed and indepth information about a number of DS sites, taking into account site documents and all data submitted by sites. Sites were selected as case study sites on the basis of agreed exclusion / inclusion criteria, developed in consultation with the DH. The aim of this was to ensure diversity in the chosen sites and allow the national evaluation team to understand different models of delivery⁴. Sites with a planned late start were excluded from the initial selection process, and a few sites indicated that they were unable to take part in the case study processes. Sites where provision was expected to focus on carers under age 18 were not included as in the case study selection process as by agreement with DH, the team did not seek ethical approval to include carers under 18 in the study.

Initially, 12 case study sites were selected as case study sites (six Breaks sites, three Health Checks sites, and three NHS Support sites). Four other case study sites were added later to enhance the study (one Breaks site, one Health Checks site and two NHS Support sites).

A first round of 'pilot' case studies (one in each type of site) was completed in September 2010. Learning from this was used to plan a second round, with minor amendments to the research instruments. All other case study visits took place between November 2010 and March 2011.

Case study sites were visited by one or more member (s) of the national evaluation team. Visits usually took one or two days and were preceded by completion of a pre-visit questionnaire by senior site staff. The questionnaire asked for detailed information about the site's activities, organisation and staffing. Based on this information, interviewees were selected to maximise diversity of staff roles and partnership organisations. In each site, the main case study visit included in-depth qualitative, semi-structured interviews with project managers; people involved in the delivery of services; and the Evaluation Liaison Officer (ELO). In some, additional meetings or observations took place. Case study visits were also used as an opportunity to collect documents from sites which had not previously been submitted to the national evaluation team, including local publicity documents and documentation developed for carers.

Survey of participating carers

Five different questionnaires were designed to capture the perceptions and experiences of carers accessing the DS services (wave one and two questionnaires for Breaks; wave one and two questionnaires for Health Checks; and one wave for NHS Support). Two Breaks sites were unable to distribute wave one of the questionnaire⁵; to ensure that carers at these sites were given an opportunity to express their opinion about the services they had

 ⁴ Inclusion criteria were based on: mode of delivery; degree of past experience; links to existing service provision; geographic / socio-economic spread; range of partnerships; coverage of identified target groups; and connection with current care debates.
 ⁵ In the Suffolk site this was due to the fact that delays in gaining ethical approval meant that the questionnaire

⁵ In the Suffolk site this was due to the fact that delays in gaining ethical approval meant that the questionnaire could not be distributed until all carers had already received their first service (and the questionnaire would therefore be irrelevant), whilst in the East Sussex site staff at the site felt particularly concerned that it was inappropriate to give questionnaires to carers when they were accessing their site services as they may be in distress.

received, a single 'combined' version of the two questionnaires was developed using questions from both waves one and two. Carers who received services from the NHS Support sites were only asked to complete a single questionnaire, covering broadly similar topics to the Breaks and Health Checks questionnaires.

All questionnaires were piloted with carers prior to implementation and their feedback on questions and length was incorporated into adaptation of the questions asked where appropriate. The evaluation methodology was designed to enable the national evaluation team to link carer survey responses to the ICRs received.

It was estimated that approximately 700 responses were required by the wave two questionnaire to generate sufficient responses to make comparisons between different 'groups' of carers (e.g. men and women). From previous experience a 50% response rate was expected to the wave one questionnaire, and 80% of these respondents were expected to agree to follow-up at wave two. Sites were allocated questionnaires based on the number of carers they expected to support during the survey period (this was difficult for some sites to estimate). In total, 1,555 questionnaires were distributed in the Health Checks sites and 1,690 in Breaks sites. Initially the evaluation team did not plan to distribute a questionnaire in the NHS Support sites (see Chapter 5, p89), but as some sites and Expert Advisers wished carers in such sites to be included in the survey a questionnaire was designed and 1,875 questionnaires were distributed in Table A.1. It is not known if all questionnaires sent to sites for distribution were actually given to carers

Quarterly calls

The quarterly calls which took place between members of the evaluation team and the Evaluation Liaison Officers (ELOs) at each site covered a range of topics. The topics of these calls are detailed in Table A.2.

Table	Table A.2 Quarterly calls conducted with DS Evaluation Liaison Officers (or equivalent)			
Call	Month	Sites number	Focus	
1	December 2009	25	Introductions; initial progress in implementing plans	
2	March 2010	25	Ethical approval processes; gathering information for local NHS Research and Development approvals.	
3	August 2010	24 ¹	Site progress in: delivery; local evaluations; target numbers; carer feedback; changes to original delivery plans.	
4	November 2010	20 ²	Partnership working; carer involvement; carer feedback; marketing.	
5	February 2011	25	Emerging outcomes; local evaluation findings; sustainability.	

Notes:

¹ A call could not be arranged with one site within the relevant period.

² Three sites involved in case study visits during the month opted not to take part; two sites did not arrange the call within the two month period allotted.

Key actor survey

The key actor survey was a postal survey designed to be undertaken by selected staff, including senior staff where possible. Each site was sent six to eight copies of the key actor survey and in total 68 were returned. Follow-up telephone interviews were conducted with a total of 15 members of staff selected to ensure the inclusion of informants from non case study sites.

Changes to the planned study

At the request of the Department of Health, the timing of the national evaluation study was shortened from 36 to 25 months. This reflected the shortened timeframe of the DS programme, but meant many aspects of the planned study had to be rescheduled. Some slippage in planned timescales later occurred due to complex ethical approval processes, mentioned above. Other changes to the design and methods originally proposed included:

- Development of a baseline document and QRT forms for each site to complete (to capture data the research team had originally expected to be available through DH monitoring arrangements).
- The responsibility the evaluation team took on for managing the DS website, at the request of the DH.
- Four additional case study sites, added in 2010 in response to lower than planned numbers of carer survey and ICR responses and in sites where additional information about innovative or distinctive activities was required.

Dissemination

The full report of the national evaluation study '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) was published on 16 November 2011 by CIRCLE, University of Leeds to coincide with a conference 'Achieving Recognition and Support for Carers' (held in Leeds on the same day).

Further information about related publications and events is available on the CIRCLE website: <u>www.sociology.leeds.ac.uk/circle</u>.

Appendix A.2 Demonstrator Site Baseline Statement

Baseline statements were sent to sites at the beginning of DS programme delivery, to capture information about carers' services already being provided.

1. Please list the services which your project plans to complete with the support of the DH Demonstrator Site funding allocated to your organisation:

Activity descriptor	Was similar / the same activity taking place in the 2 years <i>before</i> the funding started? PLEASE ANSWER YES OR NO	If answered YES in column 2, please indicate wha the activity you will be undertaking with the DH D		erent or innovative about	
1					
2					
3					
4					
5					
6					
	- ·		I	Please continue on a second si	heet if necessary
2. Which of the following stateme	nts best describes the use of DH DS fu	nding for your DH Demonstrator Site project?			
Fully-fund comple	etely new services \Box	Part-fund completely new services	her of these \Box		
3. Which of the following stateme	ents best describes DH DS funding and	any existing activities in your DH Demonstrator Sit	te project?	_	
Fully-fund specific enhancements	to existing service \Box Part-fund spe	ecific enhancements to existing service \Box Neither	er of these \Box]	

4. Which of the following statements best describes any match funding and your DH Demonstrator Site project?

Yes we have obtained some match funding $\hfill\square$

No we have not obtained match funding \Box

Appendix A.3 Demonstrator Site Quarterly Reporting Template

QRTs were sent to sites every three months to enable the national evaluation team to monitor the number of carers receiving DS services and the amount of money being spent to do this.

Carers Strategy Demonstrator Sites – National Evaluation Quarterly Reporting Template – BREAKS

National Evaluation Quarterly Reporting Template			circle		
Quarter - Demonstrator Site ID -	1st Jan- 31	st Mar 2011	CENTRE FOR INTERNATIONAL RESEARCH ON CARE, LABOUR & EQUALITIES UN		
1. <u>Carers</u>	Number this quarter (1st Jan- 31st Mar)	FINAL TOTAL (from 1st Oct 2009)	2. <u>Alternative care</u> (provided by you to enable carers to access breaks)	Number this quarter (1st Jan- 31st Mar)	FINAL TOTAL (from 1st Oct 2009)
Carers with whom your project is in contact			Carers provided with alternative care		
3. <u>Services supplied to carers</u>	3a) CARERS R BREAKS	ECEIVING		3b) BREAKS D	ELIVERED
3. <u>Services supplied to carers</u>	Number this quarter (1st Jan- 31st	FINAL TOTAL (from 1st Oct		Number this quarter (1st Jan- 31st	FINAL TOTAL (from 1st Oct
New carers	Mar)	2009)	New carers	Mar)	2009)
Carers offered a break			Breaks offered to carers		
Carers taking up such a break			Breaks taken up by carers		
Carers already in the system			Carers already in the system		
Carers offered a break			Breaks offered to carers		
Carers taking up such a break			Breaks taken up by carers		

4. Costs / spending related to providing these activities

	Spend this quarter (1st Jan- 31st Mar)	TOTAL SPEND (from 1st Oct 2009)	
osts of supplying services at 3			
f carers' involvement in planning and delivery			
ment costs of providing service (all partners)			
ng and publicity costs of providing service			
expenses (travel, alternative care, etc.) costs			
ds allocated via Direct Payments / Individual			
osts not included above (please specify overleaf)			
osts / spend in the DS			
nding or in-kind contribution made by partners			
or this period)			
eing carried forward beyond March for evaluation			
pent funds returned to DH			
pent funds kept by site			
break			
fine a 'carers break' and describe the types			

6. Please add any qualifying explanation in the below:



a) Direct cos

b) Costs of

c) Managem

- d) Marketing
- e) Carers' ex

f) Any funds Budgets

g) Other cos

h) Total cos

i) Match fun (estimate for

- j) Funds bei
- k) Underspe
- I) Underspe

5. Type of k

Please defin of breaks carers are being offered in your project here:

If you wish to send any additional documentation please email it with this form, ensuring it is clearly marked with your DS ID (to [xxxxxx]@leeds.ac.uk) or send it to: **DHDS Administrator** CIRCLE, School of Sociology and Social Policy University of Leeds Woodhouse Lane Leeds, LS2 9JT

Appendix A.4 Guidance for completion of National Evaluation Quarterly Reporting Template

This guidance was issued to sites with the first QRT and applied to all six QRT returns.

The Quarterly Reporting Template (NE QRT) is designed to collect standardised information for each Demonstrator Site about the number of carers / interventions and the amount spent in each quarter. This information will be considered, together with information about the characteristics of carers collected using the Individual Carer Record (ICR) and each DS's Baseline data, *alongside evidence from the documentary analysis of all other data provided by each DS*, to produce an holistic assessment of costs, benefits, outputs and outcomes.

Quarter data relates to	Date NE QRT sent out to sites by NET	Latest date NE QRT needs to be returned by sites to NET
1 st October – 31 st December 2009	1 st February 2010	26 th February 2010
1 st January – 31 st March 2010	31 th March 2010	30 th April 2010
1 st April – 30 th June 2010	14 th June 2010	31 st July 2010
1 st July – 30 th September 2010	13 th September 2010	31 st October 2010
1 st October – 31 st December 2010	13 th December 2010	31 st January 2011
1 st January – 31 st March 2011	14 th March 2011	30 th April 2011

Timetable for completion of NE QRT

Note:* This date will depend on the outcome of the REC.

Guidance notes on completing the NE QRT

The NE QRT is supplied to sites as an Excel spreadsheet. Please avoid moving the boxes coloured green when completing the form. Please complete NE QRTs and return them as email attachments to [XXXXX]@leeds.ac.uk, on or by the dates specified.

Section 1 Carers – this section captures information about all the carers that your project / site is in contact with (across the whole of your partnership). Note that these carers may or may not go on to take up a service you are offering.

Section 2 Alternative care provision – this refers to care / support provided by your project to enable carers to take up the service(s) you provide. Please record the costs associated with this under section 4e.

Section 3 Services supplied to carers (and to NHS Staff for NHS Support sites)

- 3a the number of carers offered a service, and the number of carers who take up a service should be recorded here.
- 3b -
 - Breaks the number of places provided / available and the number of places taken up should be included in this section.
 - Health Checks the number of health check reviews or follow-up visits undertaken should be included in this section. The type of review or follow-up is captured at 5.
 - NHS Support the number of support places or activities provided / available and the number of places taken up should be included in this section.
- 3c (For Enhanced NHS Support sites only) The number of NHS staff who have received face to training or attended 'carer awareness' sessions and those receiving carer information are recorded here. In addition, the number of Carer Support / Recognition Workers, Carers Health Leads, Carers Champions and Carer Liaison Teams in place is also capture in this section.

Section 4 - Costs / spending related to setting up and providing these activities

4a	Direct costs of supplying services at Q3	The direct costs of providing the carers' services, including staff time to provide the activity and any equipment, room bookings, or other costs required to run the activity, should be included here. This section also includes staff costs for undertaking carers health checks, arranging breaks, providing support to carers etc.
4b	Costs of carers' involvement in planning and delivery	Any costs associated with involving carers in the planning and delivery of the service should be included here.
4c	Management costs of providing service (all partners)	The costs associated with managing the service across all the partner organisations in the project; for example, the costs of employing a project manager. This should include any costs for setting the service up.
4d	Marketing and publicity costs of providing service	The amount spent marketing the service(s), including costs of producing any publicity material (across all partners).
4e	Carers' expenses (travel, alternative care, etc.) costs	Any money paid to carers to cover their travel expenses, alternative care (listed under 2), etc., should be included under this item.
4f	Any funds allocated via Direct Payments / Individual Budgets to support this activity	Include any money given to carers through direct payments / individual budgets to support these activities
4g	Other costs not included above (please specify if possible)	Any costs that are not covered by points 4a-4g should be included here with, if possible, a description in the text box provided.
4h	Total costs / spend in the DS	The total amount spent across all items (this will be the sum of 4a-4g). This should show how much has been spent this quarter (and to date).
4i	Match funding or in-kind contribution (estimate)	An estimate of any match-funding or in-kind contribution provided this quarter by any organisation outside the project partnership.

Section 5 – Type of activities delivered (these were taken from the Expected Volumes document). List the number of activities delivered by type:

- Carers Breaks please use the box at 5 to define a 'carers break' and to describe the types of breaks carers are being offered
- Carer health checks Health and Well-being checks, 6 monthly or 12 monthly follow-up visits
- NHS Support new carers identified, carers referred to existing support / carers' centre, etc.

Section 6 - Please add any qualifying explanation in the box below

- Please use the text box to provide details of any items included as 'other'
- Sites are encouraged to make use of the text box to provide additional information on any aspect of their return that they wish to provide
- Sites are also encouraged to send copies of any additional documents that they wish to be considered as part of their return, which they feel would give a more complete picture of the 'costs' and 'benefits' of their activities. Please ensure all documents supplied are clearly marked with your DS ID.

Appendix A.5 Quarterly call sample topic guide

Quarterly calls were conducted by two members of the national evaluation team. New topic guides were created every quarter to ensure the same topics were always covered in calls.

Do you have any questions for NET?

Update on Demonstrator Site progress

• Delivery of services

Progress to date / update since last call. Are the services 'winding down' as DS project comes to a close (e.g. notifying carers, referrals to other orgs), or will it be continuing with other funding?

• Carer numbers

How are you getting on with **carer numbers**? How close are they to overall target numbers aimed for (refer to revised objectives docs etc.)?

• Local evaluation

Outputs from local evaluation available so far. What have you used it for? Has it been helpful for planning, reflection, improving practice? When is final report due? How will you be sending us a copy? What do you hope it will show?

Have you managed to collect any evidence about the impact of the demo site services in terms of **cost savings**, **or potential cost savings** for services in the future?

Carer experiences

- Have you received any further feedback on how carers have experienced participating in your demonstrator sites project so far? (Any examples? Evidence of benefits? Positive / negative comments?).
- Do you have any further data on this from your local evaluation or any other sources that you would be willing to share with us?
- Do you have any further data on the characteristics of carers using your service?
- Do you know if your site engaged any carers or cared for persons who previously **selffunded their own social care**?
- Has any data been collected about carers moving onto individual budgets or direct payments following contact with the DS?
- For those **carers who have been involved** in steering and guiding the project have they had a chance to evaluate their own experiences of doing this? Will your PCT / LA continue to involve carers in service provision decisions for carers in the future?
- Have there been any further changes to the project since the last quarterly call?
- Discuss developments in any relevant / significant **issues** raised on last call (see august quarterly call records).

Thoughts on project overall (if not a recent case study interviewee)

- Overall, what has worked well?
- What has not worked well?
- Is there anything you would do differently?
- What have been the biggest lessons learned from the demo sites project? (both locally and nationally)
- Most impressive achievement?
- Greatest disappointment?

Sustainability

• Future of the project – any plans / discussions regarding extending funding / mainstreaming / continuing aspects of services?

Any comments about...

- Website
- [if not recent case study interviewee] The support role of Expert Advisers and DH.
- Long-term impact of DS at organisational level:
 - New partnerships?
 - New ways of working ?
 - New collaborations?
 - New ideas?

Participation in National Evaluation

Documentary analysis

- Chase up any outstanding documents still not sent since previous call (see template for list, and check documents on sent / on website).
- (If happy to share these documents with other Sites post on website, if they would prefer to keep private email to carersdemosites@leeds.ac.uk).
- Do they have anything new to send?

Data collection

• Chase any missing QRTs / ICRs / Surveys.

Appendix A.6Case study sample interview guide

Variations of the interview guide were developed for different types of sites and different staff roles, but the focus of the questions remained the same. One example is presented here.

NHS Support Site

Interview with ELO

Round Two- NHS SUPPORT

Question 1: ROLE OF ELO	
Please could you briefly describe your role in the Demonstrator Site se What are you main tasks?	rvices delivered by your organisation?
Managing staff	
 Networking with agencies and employers to reach new groups of exercise 	
groups of carersQuality assurance	
 Monitoring project 	
Handling client complaints	
 Reporting to senior management 	
National evaluation	
Local evaluation	
Approximately what proportion of your working responsibilities is spent How did you come to be appointed as the Evaluation Liaison Officer?	on Demonstrator Site-related tasks?
Did you volunteer or were you selected?	
If you volunteered, why did you decide to take an this rate?	
on this role?When you were initially appointed, what was	
your understanding of the role?	
Is this a new type of role for you?	
Ougetion 2: BACKCPOLIND OF OPCANISATION	
We'd like to know a little about the background and experience of your	organisation, and how you became a
We'd like to know a little about the background and experience of your Demonstrator Site.	
We'd like to know a little about the background and experience of your Demonstrator Site. Were you involved in the bidding / commissioning process (or are you	
We'd like to know a little about the background and experience of your Demonstrator Site. Were you involved in the bidding / commissioning process (or are you If so	able to comment on this)?
We'd like to know a little about the background and experience of your Demonstrator Site. Were you involved in the bidding / commissioning process (or are you If so What was your organisation's motivation to become a Demonstrator	able to comment on this)? Site?
We'd like to know a little about the background and experience of your Demonstrator Site. Were you involved in the bidding / commissioning process (or are you If so	able to comment on this)? Site?
We'd like to know a little about the background and experience of your Demonstrator Site. Were you involved in the bidding / commissioning process (or are you If so What was your organisation's motivation to become a Demonstrator	able to comment on this)? Site?
We'd like to know a little about the background and experience of your Demonstrator Site. Were you involved in the bidding / commissioning process (or are you If so What was your organisation's motivation to become a Demonstrator What was your experience of the bidding and commissioning proce	able to comment on this)? Site?
We'd like to know a little about the background and experience of your Demonstrator Site. Were you involved in the bidding / commissioning process (or are you If so What was your organisation's motivation to become a Demonstrator What was your experience of the bidding and commissioning proce • <i>Time / deadlines</i>	able to comment on this)? Site?
 We'd like to know a little about the background and experience of your Demonstrator Site. Were you involved in the bidding / commissioning process (or are you If so What was your organisation's motivation to become a Demonstrator What was your experience of the bidding and commissioning process Time / deadlines Bureaucracy and paperwork Dealings with the Department of Health 	able to comment on this)? Site?
We'd like to know a little about the background and experience of your Demonstrator Site. Were you involved in the bidding / commissioning process (or are you If so What was your organisation's motivation to become a Demonstrator What was your experience of the bidding and commissioning proce • <i>Time / deadlines</i> • <i>Bureaucracy and paperwork</i> • <i>Dealings with the Department of Health</i> Do you know why your organisation was selected?	able to comment on this)? Site? ess for the Demo Sites programme?
We'd like to know a little about the background and experience of your Demonstrator Site. Were you involved in the bidding / commissioning process (or are you If so What was your organisation's motivation to become a Demonstrator What was your experience of the bidding and commissioning proce • <i>Time / deadlines</i> • <i>Bureaucracy and paperwork</i> • <i>Dealings with the Department of Health</i> Do you know why your organisation was selected? How different is the Demonstrator Site project from your organisation'	able to comment on this)? Site? ess for the Demo Sites programme?
We'd like to know a little about the background and experience of your Demonstrator Site. Were you involved in the bidding / commissioning process (or are you If so What was your organisation's motivation to become a Demonstrator What was your experience of the bidding and commissioning proce • <i>Time / deadlines</i> • <i>Bureaucracy and paperwork</i> • <i>Dealings with the Department of Health</i> Do you know why your organisation was selected?	able to comment on this)? Site? ess for the Demo Sites programme?
If so What was your organisation's motivation to become a Demonstrator What was your experience of the bidding and commissioning proce • <i>Time / deadlines</i> • <i>Bureaucracy and paperwork</i> • <i>Dealings with the Department of Health</i> Do you know why your organisation was selected? How different is the Demonstrator Site project from your organisation' • <i>What is new / different about the project?</i> • <i>Has your organisation carried out any similar initiatives in the p</i>	able to comment on this)? Site? Sites for the Demo Sites programme? s previous initiatives?
 We'd like to know a little about the background and experience of your Demonstrator Site. Were you involved in the bidding / commissioning process (or are you If so What was your organisation's motivation to become a Demonstrator What was your experience of the bidding and commissioning proces Time / deadlines Bureaucracy and paperwork Dealings with the Department of Health Do you know why your organisation was selected? How different is the Demonstrator Site project from your organisation'	able to comment on this)? Site? Sites for the Demo Sites programme? s previous initiatives?

Question 3: CONNECTION WITH NATIONAL STRATEGY

How do you feel the Demonstrator Sites project relates to the broader aims of the National Strategy for Carers (as outlined in June 2008 document '*Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own'*)?

- Improve carers' health and emotional well-being
- Improve carers' quality of life
- Recognise the contribution carers make
- Increase carers' choice and control
- Benefit carers' economic well-being

Are there any other similar provisions in your local area?

- How does your NHS support service support with the specific needs of carers in your local area?
- What are the specific needs in your area?
- Can you provide examples?

Question 4: ORGANISATIONAL IMPACT / STAFF RESPONSES

We'd like to know more about the **impact** the Demonstrator Sites project has had on your own organisation and how it **fits** with the work you do here

How has the NHS support for carers impacted on:

- The work your department / organisation does?
 - Impact on other carers' services your organisation offers
 - o General role of your department / organisation
- YOUR workload and the workloads of OTHER STAFF (examples)
 - Impact of NHS staff training on staff work-loads / staff roles
 - \circ $\;$ Impact of working with carers / carer leads / NHS staff
 - o Additional referrals
 - New procedures for identifying / referring carers
- PERSPECTIVES of staff have any responded more positively than others to the project and why?
 - 0
 - GPsHospital staff
 - Nurses
 - o Carer liaison workers / support workers
 - Voluntary sector staff

How does your organisation monitor the delivery of your services?

- Number of training sessions delivered
- Number of staff / carers trained
- Feedback from carers
- Increased referrals to carer services

Have you had to develop new systems of working to meet these arrangements (i.e. Management Information (MI) requirements)?

- Database
- Infrastructure
- Staff
- Account / finance systems

Question 5: BUDGET	
Are you involved in the budgetary or fi comments about these)? If yes	inancial arrangements at your Demonstrator Site (or do you have any
	ements work for the NHS support project?
	• Where and what are the costs involved in delivering your service?
	• Is the funding from the Department of Health for the Demonstrator Sites Project ring fenced at a local level within your site?
	• Does the funding you receive cover all of the costs involved in delivering the project?
	What are the typical costs of: staff training, producing information for carers / staff, the upkeep of the website / information line?
	Contractual arrangements with external organisation providing / maintaining these services.
How do you feel these arrangements a	
Have there been any unanticipated of	
	or your Demonstrator Site services with the Department of Health? Or
with your partnership organisations?	
Were these issues resolved?	fotose hudent en entintin en O
Do you anticipate making any	
How do you monitor finances?	
Staff costsAdmin costs	
 Fieldwork costs for local 	
 Fieldwork costs for local evaluation 	What do you ask staff / partners to monitor? And how?
Service delivery costs	 What do the Department of Health / Expert Adviser
 Any other costs 	require?
Has there been any budget 'carry-ove	er' (or under-spend) during this project?
Why has there been an under	•
	ment of Health) dealt with this? , been any cost shunting regarding other local carer provision?

• Has there, to your knowledge, been any **cost shunting** regarding other local carer provision?

Question 6: RELATIONSHIP WITH DEPARTMENT OF HEALTH / EXPERT ADVISERS

Do you have any direct contact with the Expert Advisers? If yes...

What do you understand to be their role?

Do you have any comments about this role?

How has your **relationship** with the Department of Health and the Expert Advisers **developed** during the project?

What **impact**, if any, has your Expert Adviser had on the **delivery** of the service in your organisation? Can you provide examples?

Question 7: PARTNERSHIP WORKING

Why did you decide to work with [XXXX]?

Have you worked in this way before?

How is this relationship with [XXXX] developing?

- Can you provide **examples** of what is working **well**?
- Can you provide **examples** of what is **not working well**?
- Are the **funding** arrangements appropriate?

Question 8: REACHING CARERS

Why have you decided to target particular carers?

Are you are involved in identifying carers? If yes

Did you have an existing database of carers / known carers before this project started?

If YES, how have you utilised this database? How have you identified any carers in other ways?

If NO, how did you go about identifying and / or targeting carers?

What strategies have you used to;

- Identify and access target groups of carers
- Identify and access 'hard-to-reach' carers
- Increase the number of carers receiving Demonstrator Site services
 PLEASE PROVIDE EXAMPLES
- What was the rationale for using this strategy?
- How **successful** has this strategy been?
- If not, why not? If so, why?
- Are any of these strategies particularly **innovative**?
- Have you made any changes to the way you recruit carers in comparison with your previous services?

Question 9: CARER INVOLVEMENT

Have you included carers in the design and delivery of your NHS support service?

- If so, to what extent?
- What do you feel is the benefit of this?
- Consultation
- Needs assessment
- Carer feedback
- Delivering health checks
- Carers as researchers

Question 10: B	
What do you se	ee as being the main benefits of your NHS Support project?
•	For CARERS (now and in the future)
	 Improved access to information Better support Greater recognition of carer needs Improved health and well being Improved quality of life Recognition of carers as expert partners Maintain and sustain caring roles
•	For YOUR ORGANISATION (now and in the future)
	 Less need for emergency treatment for carers Increase in early diagnosis of health conditions among carers More efficiency in treating health conditions among carers
•	For the HEALTH AND SOCIAL CARE SYSTEM? (now and in the future)
SERVICE	 Cultural change in the NHS / improving services by integrating carers into current practice Recognition of carers as expert partners Better informed professionals Improvement in working relationships and co-ordination between NHS / carers / voluntary organisations Better procedures for identifying, registering and referring carers early on, leading to earlier diagnosis / preventing carer breakdown More effective training for NHS staff Increase in numbers of Carer's Assessments
Have there bee	en any limitations or negative consequences in the project design and delivery so far?
•	For CARERS
•	For YOUR ORGANISATION
•	For the HEALTH AND SOCIAL CARE SYSTEM?
Have any of the	ese positive or negative outcomes been unexpected ?
•	What are the implications of this?
How are you e v	videncing these benefits and outcomes?

Question 11: LOCAL EVALUATION

What, if any, has been your role so far in the local evaluation?

What methods and data sources are you using?

How is the local evaluation developing?

What are you hoping to find out?

Do you have any plans to **produce a report** of these findings? If yes, what plans to you have (if any) to **disseminate** your results? Can this report be made available to the NET?

Question 12: NATIONAL EVALUATION				
We'd also like to hear about your experience of national evaluation activities				
As the Evaluation Liaison Officer, in what ways have you engaged with the National Evaluation so far?				
Data gathering				
Providing information on website				
Updates via phone / email				
Ethical approval				
How has this fitted into your broader role in the Demonstrator Site?				
Fit with local evaluation research				
 Amount of time spent in relation to this 				
Impact on delivery				
Prior to the National Evaluation beginning, what did you expect it to involve?				
Has your experience of the National Evaluation differed from your expectations?				
In what ways has your understanding of the National Evaluation changed?				
Did you attend the NET's contact event in February 2010 in Leeds?				
If yes;				
Was it useful?				

• Did it help your engagement with the National Evaluation?

Question 13: SUSTAINABILITY

Are you in discussions about and / or planning to sustain the NHS Support service, beyond the timeframe of current DHDS funding?

How realistic do you think these discussions / plans are?

- What will this depend on?
- What sort of issues might you face?

What is the value, if any, in sustaining the project?

Question 14: FINAL QUESTIONS

To sum up - based on the first few months of your Demonstrator Site activities, can you provide **examples** of aspects which are:

- Are working **well**?
- Are **not** working well?
- Are innovative?

If you had the opportunity to start this project **again**, is there anything you would do **differently**?

Do you anticipate any **significant challenges** arising in the next months or year in successfully delivering the Demonstrator Site services?

Do you have any other comments you would like to make?



Department of Health Demonstrator Sites – National Evaluation

Carer's Questionnaire – Carers' Breaks (Stage 1)

To find out if the Demonstrator Sites programme is a good scheme for carers of sick, disabled or older people, the Department of Health has commissioned the University of Leeds to assess how effective the programme is. The study is designed to investigate what benefits carers gain from taking part in the Demonstrator Sites programme, especially whether the programme helps carers to maintain their own health and well-being and that of the person they care for; and have 'a life of their own'.

If you choose to return this questionnaire, you will be giving permission for the research team to have access to your confidential responses. All your answers will be treated in strict confidence by the study team. We will not use your name or identifiable personal details in any report of this work, and nobody else will know who took part in this study. You can withdraw from the study at any time without affecting any support that you are entitled to in any way. You do not have to give a reason.

Sectio	Section 1 – Your caring situation					
In the last week, how many hours of care do you estimate you have provided? (by 'care' we mean providing support or assistance to someone in poor health and/or has a disability or someone who is frail because of old age) Hours of care in the last week						
2 F	low many people do ye	ou currently care for	?			
One	person	Two people	Three o	r more peo	ple	
In questions 3 and 4 please answer for each person you care for. (If you care for more than 3 people, please answer for the 3 people you provide the most care for.)						
-	-				are for mo	re than 3
people, p	lease answer for the 3	people you provide th			Person	Person
people, p	-	people you provide th		for.)		
people, p	lease answer for the 3	people you provide th		for.)	Person	Person
people, p	lease answer for the 3	people you provide th	ne most care	for.)	Person	Person
people, p	Nease answer for the 3	people you provide th	e most care Yes No	for.) Person 1	Person 2 □	Person
geople, p	lease answer for the 3	people you provide th	e most care Yes No	for.) Person 1	Person 2 □	Person
people, p	Nease answer for the 3	people you provide th	e most care Yes No	for.) Person 1 	Person 2 — — ou?	Person 3

No

5 role? By a 'break' we mean either that someone else provided the care you normally give (by providing a sitting service for a few hours or respite care, enabling you to do something you wanted to do for yourself), or that you were able to get away from your everyday routine for a holiday or short break (either with or without the person you care for). Please tick one box only No Yes, for a few hours Yes, I could be away for a whole day if I wish Yes, I could be away overnight if I wish Yes, I could have a holiday or weekend break from time to time Before accessing the service when, if ever, did you last have a break from your 6 regular caring routine? Please tick one box only Never Within the past week More than a week ago, but within the past month More than a month ago, but within the past 6 months More than 6 months ago, but within the past year More than a year ago Section 2 – Your own health and wellbeing Do you have any long-term illness, health problem or disability which limits 7 your daily activities or the work you can do? (Include problems which are due to old age.) Yes No For each of the following statements, please indicate which box is closest to 8 how you have been feeling over the last two weeks.⁶ Some of More than All of At no Less than Most Over the last two weeks... the time half of the half of the of the time the time time time time I have felt cheerful and in good spirits I have felt calm and relaxed I have felt active and vigorous I woke up feeling fresh and rested My daily life has been filled with things that interest me

Before accessing the service were you ever able to take a break from your caring

⁶ This scale is called the WHO-Five Well-Being Index.

Section 3 – The Carers' Break Service						
9 How did you find out about the	service?					
Local doctor/GP	Internet Advertisement A friend/relative Other (please specify below)					
10 Did the break provider contact y or did you contact them about a	you about accessing a break they have available accessing a service? They contacted me					
	ak you had or will have as part of this service.					
12 Please answer each of the follo	wing questions about accessing the service <i>:</i>					
	Strongly Agree Neither Disagree Strongly agree agree nor disagree					

	agree	agree nor disagree	disagree
The Carer Breaks service was easy to find out about			
It was easy to book a break			
It was easy to contact someone to help me find a break			
The staff were able to help me find the right break to suit my needs			
I would recommend this service to other carers			

13 Do you have any additional comments you would like to make about *Carers' Break Service*? If so, please write them here (continue on a separate sheet if you wish). We would be very interested to hear what you have to say.

Sectio	n 4 About yo	u			
14	Date of birth	Day	Month	Year	
15	Postcode				
16	Are you? Male			Female	

We hope that most carers completing this questionnaire will **be willing to be contacted again** for the next phase of our survey. This will help us find out about any lasting or long-term benefits of *Carers Breaks*. If you **are willing to be contacted again**, please supply your contact details below.

Title							
First name							
Surname/ family name							
Address							

Thank you for completing this questionnaire. Please return it, using the reply paid envelope supplied, within the next *two weeks* to: XXXXX, Project Administrator, CIRCLE, School of Sociology and Social Policy, University of Leeds, Leeds, LS2 9JT.

Carers Direct helpline

Free, confidential information and advice for carers

Call the Carers Direct helpline on **0808 802 0202** if you need help with your caring role and want to talk to someone about what options are available to you. You can also contact Carers Direct by textphone on 0800 988 8657.

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or email Carers UK at:

adviceline@carersuk.org

Carer's questionnaire – Carers' Break Service Stage 2







Department of Health Demonstrator Sites – National Evaluation

Carer's Questionnaire – Carers' Break Service (Stage 2)

Thank you for returning the first questionnaires about Carer's Break Service, and for agreeing to be contacted again.

To help us understand whether Carer's Break Service has a long-term benefit for you, we need to collect information about your circumstances and caring situation, your health and wellbeing, and your views about the service and its effects.

All your answers will be treated in strict confidence by the study team. We will not use your name or identifiable personal details in any report of this work, and nobody else will know who took part in this study. You can withdraw from the study at any time without affecting any support that you are entitled to in any way. You do not have to give a reason.

Section 1 – Changes to your circumstance and caring situation

1 In the last week, how many hours of care do you estima 'care' we mean providing support or assistance to someone in disability or someone who is frail because of old age)	•	•	· •
Hours of care in the last week			
2 Since we last contacted you, has the amount of time you	u spend	caring	
Increased Increased Stayed Decrease a lot a little the same a litt		Decrea: a	sed
3 Since we last contacted you, how would you describe the of the person(s) you care for? Please answer for each per for more than 3 people, please answer for the 3 people you p	son you	care for. If	you care
	Person 1	Person 2	Person 3
Their health/disability has not changed			
Their health/disability has become worse			
Their health/disability has improved			

Section 2 – Your own hea	Section 2 – Your own health and wellbeing							
4 Over the last six months would you say your own health on the whole has been: Good Fairly good								
5 For each of the following statements, please indicate which box is closest to how you have been feeling over the last two weeks. ⁷								
Over the last two weeks	At no time	Some of the time	Less than half of the time	More than half of the time	Most of the time	All of the time		
I have felt cheerful and in good spirits								
I have felt calm and relaxed								
I have felt active and vigorous								
I woke up feeling fresh and rested								
My daily life has been filled with things that interest me								

Section 3 – Your views about the Carer's Break Service

Please describe the type of break(s) you had as part of this service.

7 When was the last time you used the breaks service?

Please tick one box only



 $^{^{\}rm 7}$ This scale is called the WHO-Five Well-Being Index.

6

How long did this last break last?

Please tick one box only



How many times have you used this breaks service in the last 6 months?

10 Please answer each of the following questions about the breaks service you received:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
The services were tailored to my needs					
The break was enjoyable					
The break was easy to access (in terms of getting to the venue)					
The service and staff were understanding of my caring situation					
I would recommend this service to other carers					

11 Do you think that the Breaks Service could be improved in any way? Please give examples:



9

Section 4 – Your views about the effect Carer's Break Service have had on your own health, wellbeing and your ability to have a "life on your own"

12 We would like to know if you feel that, as a result of the Carer's Break Service you have received, there have been any effects on the following aspects of <u>your own</u> <u>life</u>:

Please let us know about each of the following:	Yes	No	No change
I have more time for myself			
The balance between my caring and other relationships (family or friends) has improved			
My social life is better			
I have joined a new club or social group			
I have started a new hobby or leisure activity			
I feel more confident about my ability to take on new challenges			
I have applied for a new training course (e.g. NVQ, evening classes)			
I have begun a new training course			
I have become/applied to become a student in further or higher education			
I have started volunteering			
13 Do you feel that the Carer's Break Service you have receive <u>life</u> in any other ways?	ed has a	affected	l <u>your own</u>
Yes No	Not sur	e	
If yes, in what other ways has <i>your own life</i> been affected?	Please	comme	ent below

14 Please tell us if you feel that, as a result of the Carer's Break Service you have received, there have been any effects relating to *paid work*:

Please let us know about each of the following:	Yes	No	No change	Not applicable
I am considering returning to paid work				
I have applied for a new paid job				
I have started a new paid job				
I have negotiated a flexible working arrangement with my employer or reduced the number of hours I work				
I have increased the number of hours I work				

Please tick the 'not applicable' boxes as appropriate

15 We would like to know if you feel that, as a result of the Carer's Break Service you have received, there have been any effects on <u>your own health and wellbeing</u>:

Please let us know about each of the following:	Has improved	Has not changed	Has got worse
The way I look after my own health			
My general health			
The way I take care of myself			
How I feel about life			
My diet			
The way I deal with stress			
My ability to cope			
Taking regular exercise			
My ability to relax			

16 Do you feel that the Carer's Break Service you have received has affected <u>your</u> <u>health and wellbeing</u> in any other way?

Yes	No 🗌	Not sure					
If yes, in which other ways have <i>your health and wellbeing</i> been affected?							

17 We would like to know if you feel the Carer's Break Service you have received has had any effects on *your caring role*:

Please let us know about each of the following:	Has improved	Has not changed	Has got worse
The care I give			
My understanding of carers' rights and entitlements			
My knowledge about how to access support and Carer's Break Service			
My communication with professionals and service providers			
The support I get from professionals and service providers			
The breaks or respite I get			
My understanding of how to access local information and support			
If yes, in what other ways has <u>your caring role</u> bee		you have re	ceived has
had any effect on the person you provide most car	<u>re for</u> .		
Please let us know about each of the following:	Has improved	Has not changed	Has got worse
Their quality of life			
My ability to take care of them			
My relationship with them			
The standard of care I give them			
Their independence			
The dignity and respect with which they are treated			
The choices they have about their care			

20		Carer's Break Service you ha <u>nost care for</u> in any other ways?	ve received has affected the
	Yes	No	Not sure
	If yes, in what other w	vays have they been affected?	
21	consequences? (For e	ng a break from your caring role example, the person you care for ge a are spending time away from them	ts upset when you are not there
	Yes	No 🗌	Not sure
	If yes, can you descri	be these below?	
22	Break Service? If so,	itional comments you would like please write them here (continue ery interested to hear what you h	e on a separate sheet if you

Section 5 About you					
23	Date of birth	Day	Month	Year	
24	Postcode				
25	Are you? Male			Female	

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adviceline@carersuk.org

Registration number	
CENTRE FOR INTERNATIONAL RESEARCH ON CARE, LABOUR & EQUALITIES	UNIVERSITY OF LEEDS

Department of Health Demonstrator Sites – National Evaluation

Carer's Questionnaire – Health checks (Stage 1)

To find out if the Demonstrator Sites programme is an effective scheme for carers of sick, disabled or older people, the Department of Health has commissioned the University of Leeds to assess it. This evaluation is designed to investigate what benefits carers gain from taking part in the Demonstrator Sites programme, especially whether the programme helps carers to maintain their own health and well-being and that of the person they care for, and to have 'a life of their own'.

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Section 1 – Your caring situation						
In the last week, how many hours of care do you estimate you have provided? (by 'care' we mean providing support or assistance to someone in poor health and/or has a disability or someone who is frail because of old age) Hours of care in the last week						
2	How many people do you currently care for?					
On	e person 🗌 Two people 🗌 Three	or more peo	ple			
In questions 3 and 4 please answer for each person you care for. (If you care for more than 3 people, please answer for the 3 people you provide the most care for.)						
3	Are you the main carer for this person(s)?	Person 1	Person 2	Person 3		
3	Yee Yee the main early for the percent(c):	s				
	N	⊳ □				
4 Does the person(s) you care for live in the same household as you?						
		Person 1	Person 2	Person 3		
	Ye	s		Ū		
	Ν	□ □				

Section 2 – Your own health and wellbeing						
5 Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do? (Include problems which are due to old age.)						
6 Over the last twelve n been: Good		would you	say your o	wn health o Poo		le has
	i any					
7 For each of the follow how you have been fe					ox is clos	sest to
Over the last two weeks	At no time	Some of the time	Less than half of the time	More than half of the time	Most of the time	All of the time
I have felt cheerful and in good spirits						
I have felt calm and relaxed						
I have felt active and vigorous						
I woke up feeling fresh and rested						
My daily life has been filled with things that interest me						
8 When was the last ti health (please exclude a	•		•		about you	ır own
Within the last Within the 2 weeks last month		Vithin the las 6 month	st 🗌 With	in the it year	More than a year ago	
9 Have you ever had a health check before? Yes Please go to question 10 No Please go to question 11						
10 How long ago was your last health check – please specify below? Within the last Within the 2 weeks Within the 10 Within the						

⁸ This scale is called the WHO-Five Well-Being Index.
Section 3 – The Carers Health Checks Service								
11 How did you find out about the service?								
Local doctor/GP								
At the hospital				Advertiseme	nt			
Social Services			A	friend/relativ	/e			
Carers' centre		С	ther (please	specify belov	v)			
12 Did the provider contact you about receiving a health check or did you contact them about receiving a health check?								
I contacted them They contacted me								
13 Please answer each of the follo	wing ques	tions ab	out access	ing the serv	vice <i>:</i>			
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree			
The Carers Health check service was easy to find out about								
It was easy to contact someone to help me find a health check in my area								
It was easy to book a health check								
I think the information about the health check was easy to understand								
I think this service is a good way to support carers health								
I would recommend this service to other carers								

Do you have any additional comments you would like to make about *Health Checks Service*? If so, please write them here (continue on a separate sheet if you wish). We would be very interested to hear what you have to say.



Section 4 About you								
15	Date of birth	Day	Month	Year				
16	Postcode							
17	Are you? Male			Female				

We hope that most carers completing this questionnaire will **be willing to be contacted again** for the next phase of our survey. This will help us find out about any lasting or long-term benefits of *Health Checks*. If you **are willing to be contacted again**, please supply your contact details below.

Title								
First name								
Surname/ family name								
Address								

Thank you for completing this questionnaire. Please return it, using the reply paid envelope supplied, within the next *two weeks* to: XXXXXX, Project Administrator, CIRCLE, School of Sociology and Social Policy, University of Leeds, Leeds, LS2 9JT.

Carers Direct helpline

Free, confidential information and advice for carers

Call the Carers Direct helpline on **0808 802 0202** if you need help with your caring role and want to talk to someone about what options are available to you. You can also contact Carers Direct by textphone on 0800 988 8657.

The helpline is open from 8am to 9pm Monday to Friday, and from 11am to 4pm, at weekends. Calls from UK landlines and Vodafone, O2 and T-Mobile mobile phone networks are free.

Carers UK

A national charity, Carers UK is a membership organisation of carers, led by carers, for carers. Carers UK has a helpline for carers. If you need advice about your caring situation you can call Carers UK on

0808 808 7777

or email Carers UK at:

adviceline@carersuk.org

Registration number	
CENTRE FOR INTERNATIONAL RESEARCH ON CARE, LABOUR & EQUALITIES	UNIVERSITY OF LEEDS
Department of Health Demonstrator Sites	 National Evaluation

Carer's Questionnaire – Health Checks (Stage 2)

Thank you for returning the first questionnaire about Health Checks Service, and for agreeing to be contacted again. To help us understand whether the Health Checks Service (in some places this is called a "Health and Wellbeing Check") has a long-term benefit for you, we need to collect information about your circumstances and caring situation, your health and wellbeing, and your views about the service and its effects.

All your answers will be treated in strict confidence by the study team. We will not use your name or identifiable personal details in any report of this work, and nobody else will know who took part in this study. You can withdraw from the study at any time without affecting any support that you are entitled to in any way. You do not have to give a reason.

1	In the last week, how many hours of care do you estin we mean providing support or assistance to someone in p someone who is frail because of old age)				
	Hours of care in the last week				
2	Since you filled out the first questionnaire about the amount of time you spend caring	e Health	Checks	Service,	has the
In	creased Increased Stayed Decreas a lot a little the same a lit		Decre	ased a lot]
3	Since you filled out the first questionnaire about the H you describe the health and/or disability of the person each person you care for. If you care for more than 3 people provide the most care for.	n(s) you ca	are for?	Please a	nswer for
		F	Person	Person	Person
			1	2	3
	Their health/disability has not c	changed			
	Their health/disability has become	e worse			
	Their health/disability has in	nproved			

Section 2 – Your own health and wellbeing								
4 Over the last twelve months would you say your own health on the whole has been:								
Good	Fairly	good			Poor			
5 For each of the following statements, please indicate which box is closest to how you have been feeling over the last two weeks. ⁹								
Over the last two weeks	At no time	Some of the time	Less half o tin	of the	More than half of the time	Most of the time	All of the time	
I have felt cheerful and in good spirits			Ľ]				
I have felt calm and relaxed								
I have felt active and vigorous]				
I woke up feeling fresh and rested]				
My daily life has been filled with things that interest me]				
Section 3 – Your views about the Health Checks Service								
6 Please answer each of the following questions about the Health Check service:								
		Strongly agree	Agree		er agree sagree	Disagree	Strongly disagree	
The Health Check service was tailor my n								
The Health Check(s) was conducted pleasant ma				Ľ				

pleasant manner			
The Health Check(s) was easy to access (in terms of getting to the venue)			
The service and staff were understanding of my caring situation			
I would recommend this service to other carers			

7	In my health check(s) we covered the following:			
	I	Yes	No	Don't know
	Physical health			
	Stress and emotions			
	Mental health			
	General wellbeing			
	Safety in being a carer (e.g. lifting and handling)			
	Lifestyle (e.g. diet, smoking, drinking)			

 $^{^{\}rm 9}$ This scale is called the WHO-Five Well-Being Index.

8 As part of your health check(s), did any of the following happen and (if yes) how useful do you feel it was?

<i>Please let us know about each of the following:</i>	Yes and it was very useful	Yes and it was of some use	Yes but it was of little or no use	l didn't receive this type of support
I was signposted to additional services or support				
I received advice on how to manage my health				
I was helped to construct a health plan				
I was offered a follow up appointment				
I was prescribed new medication/ treatments				
I was referred to another medical practitioner				
9 Did the health check(s) identify a previously know about? Yes Please give further details b			dition(s) which	ch you did not
10 Did the health check(s) allow you to Yes Please give further No details below if you wish No	o 🗌 Please	n g that was give further w if you wish	l did n	o you? ot have
11 We would like to know if you feel th received, there have been any effect				ervice you have
·	Has	improved	Has not	Has got worse
Please let us know about each of the following			changed	
The way I look after my own he				
My general he				
The way I take care of my	/self			
How I feel about				
Mv	t life			
iviy	t life diet			
The way I deal with st	diet			
·	diet ress			

Please write any additional comments you would like to make about the health checks
service here (continue on a separate sheet if you wish).

Section 4 About yo	u		
13 Date of birth	Day Month	Year	
14 Postcode			
15 Are you? Male		Female	

Thank you for completing this questionnaire. Please return it, using the reply paid envelope supplied, within the next *two weeks* to: XXXXXX, Project Administrator, CIRCLE, School of Sociology and Social Policy, University of Leeds, Leeds, LS2 9JT.

Carers Direct helpline	Carers UK
 Free, confidential information and advice for carers Call the Carers Direct helpline on 0808 802 0202 if you need help with your caring role and want to talk to someone about what options are available to you. You can also contact Carers Direct by textphone on 0800 988 8657. 	A national charity, Carers UK is a membership organisation of carers, led by carers, for carers. Carers UK has a helpline for carers. If you need advice about your caring situation you can call Carers UK on 0808 808 7777
The helpline is open from 8am to 9pm Monday to Friday, and from 11am to 4pm, at weekends. Calls from UK landlines and Vodafone, O2 and T-Mobile mobile phone networks are free.	or email Carers UK at: adviceline@carersuk.org



Department of Health Demonstrator Sites – National Evaluation Key actor survey

This survey is designed to find out the views and experiences of the key members of staff who are involved in the Carers Strategy Demonstrator Sites projects. We are keen to receive your views and opinions on how well you think the project is working, how it has impacted on your job role and work load, and any changes experienced in your organisation and its provision of services to carers. Through this, the survey aims to increase understanding of how new initiatives like the Carers Strategy Demonstrator Sites projects affect service delivery and working relationships in health and social care.

The survey is entirely voluntary, and you can withdraw at any time, and do not have to give a reason. If there is any question you do not wish to answer (or feel unable to answer) please just leave it blank. If you choose to return this questionnaire, you will be giving permission for the research team to have access to your confidential responses. All your answers will be treated in strict confidence by the study team and we will not share this information with anybody else. The information you give us will be stored on a secure computer at the University of Leeds, which can only be accessed by researchers in the study team. We will not use your name or identifiable personal details in any report of this work. However, organisations may be recognizable to some readers and so, on the basis of your role, you should be aware that comments you make could potentially identify you.

I have read and understood the above, and give consent to participate:

Participant's Signature:

Date:

Sec	tion 1 Backgroun	d information			
1 Unde	Age group? er 20 20 -34	35-44	45-54	55-64	65 or
2	Are you…?	Male	Female		
		the Demonstrator Site m part of your role, and local council etc)			

Sec	ction 2 Impact of the Demonstrator Site project on your job role
5	Were you employed in the same organisation prior to the Demonstrator Site project?
lf ye	es, please continue at question 6. If no please skip to question 11.
6	How has your job role changed since taking part in the Demonstrator Site project?
7	Has your workload increased or decreased since you became involved in the Demonstrator Site project?
	Increase in No change in Decrease in workload workload workload
8	Have there been any changes in the organisation of your work activities as a result of the Demonstrator Site project?
	Yes (please explain below)
9	Can you describe any improvements in the services and support you personally can offer to carers as a result of the Demonstrator Site project?

Has the Demonstrator Site project had any negative implications on your ability to deliver services and/or support to carers (e.g. less time to support carers, excessive administrative activities etc...)?

10

Section 3 Impact of the Demonstrator Site project on your organisation

This section refers to the broader organisation(s) you currently work for and how the Demonstrator Site project has impacted on this organisation, rather than just the specific Demonstrator Site project team.

11 How has the Demonstrator Site project impacted on the type of work the organisation(s) you work for does?

How has it impacted upon the size of the workloads of other staff members in the organisation(s) you work for? 12 Increase in staff No change to Decrease in staff workloads staff workloads workloads Have there been any changes in the organisation of staff roles and 13 responsibilities in this organisation(s) as a result of the Demonstrator Site project? No Not sure Yes (please explain

Has the Demonstrator Site project led to any new partnerships or ways of 14 working with other organisations, for example new work with: (Please tick all that apply) Carers organisations Local authority staff

Other third sector organisations Local businesses Hospital staff Community organisations GP practice staff Faith groups Other NHS staff BME groups

Other (please state below)

below)

15 If you ticked any boxes in response Q14, to what extent have these new collaborations improved delivery of carers' services/support (both Demonstrator Site and other services) by the organisation(s) you work for?

Has the organisation(s) you work for experienced any challenges or difficulties in 16 implementing the Demonstrator Site services? (If yes please highlight what you feel are the most important challenges here, which may include broad or smaller/specific issues, and please continue on a separate sheet if necessary) Yes No Please explain your answer in the space below:

Section 4 Benefits of the Demonstrator Site project for carers

17

To what extent (if any) do you agree that, as a result of the Demonstrator Site Project, support for each of the following has improved for carers in the areas you work in?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not applicable to my Site	Don't know/ unable to say
a) Health and wellbeing							
 b) Recognition of their needs 							
 c) Access to information regarding services and support 							
d) Ability to take a break							
e) Their quality of life							
 f) Quality of life of cared for persons 							
g) Ability to maintain and sustain caring roles							
h) Relationships with family/ cared for persons							
i) Access to employment/training/ education							
j) Choice and control over access to services							
 k) Sense of control over their own life 							
l) Other (please specify below)							

18

Can you give some key examples of any improvements for carers identified in Q17?

Section 5 Benefits of the Demonstrator Site project for the health and social care system

19

To what extent would you agree that there have been any of the following improvements in health and social care organisations you are in contact with, as a result of the Demonstrator Site Project?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not applicable to my Site	Don't know/ unable to say
a) Recognition of carers as expert partners							
 b) Understanding of carer needs, rights and issues 							
c) Information and training for NHS staff working with carers							
d) Working relationships and co-ordination between NHS/ carers/ third sector organisations							
e) Procedures for identifying, registering and referring carers to further support							
f) Earlier identification of physical or mental health issues among carers							
g) Provision of practical/emotional support to address well-being issues							
h) Increase in numbers of Carers Assessments completed							
 i) Reduction in emergency care / residential care admissions 							
j) Other (please specify)							

Can you give some key examples of any organisational improvements identified in Q19?

Which of the benefits mentioned in Q19 (or your reply to Q20) do you see as the 21 most significant for the future development of the health and social care system? Section 6 Cost implications 22 Are you involved in funding/budget decisions at the Demonstrator Site? Yes No If yes, please continue at question 23. If no please skip to question 27. How effectively have the funding/budget arrangements for the Demonstrator Site 23 project worked? Very Effectively Neither Ineffectively Very effectively effectively ineffectively nor ineffectively Has the funding you receive covered all of the costs involved in the project? 24 Yes To some extent No If not, please can you provide further details?

25	Have there been any unexpected costs	in developing and	delivering the project?
	If yes, please can you provide further d	letails?	
26	Have you noticed any evidence of cos Site project?	st-savings as a res	ult of the Demonstrator
	Yes	No 🗌	Not sure
	If yes, please could you give any exam	ples or evidence of	these?
27	Do you have any comments on any oth you feel have not been covered in the a additional comments you would like to Demonstrator Site project? If so, pleas separate sheet if you wish.	above questions, or make about your e	any other experience of the

Thank you for completing this questionnaire. Please return it, using the reply paid envelope supplied to: XXXXX, Project Administrator, CIRCLE, School of Sociology and Social Policy, University of Leeds, Leeds, LS2 9JT.

We will be conducting **follow up telephone interviews** to explore some of the issues in this survey in greater depth. If you are happy to be contacted for this purpose, please give details of your name and contact details below:

Title								
First name								
Surname/ family name								
Telephone number								
Email address								

Appendix A.12 Expert Adviser interview schedule

Question 1: YOUR ROLE

Very **briefly**, how would you describe your role as Expert Adviser? *What were your main tasks*?

- Managing sites
- Collecting site MI data
- Engaging sites in networking events
- Quality assurance
- Monitoring
- Handling site complaints
- Reporting to DH

Was the allocated 2 days a week sufficient time for the Expert Adviser role? Did you ever have to spend longer than the allocated time? If yes, how frequently? What was the impact when your time was reduced to 1 day per week?

How did you become involved in this role?

Was there any conflict of interest between your role as Expert Adviser and any other roles you may have?

Question 2: Set up of Demonstrator Sites

What was your role in the bidding / commissioning process for the Demonstrator Sites project?

How well did you feel that the **bidding and commissioning process** for the programme worked for the sites?

- Realistic timeframes and deadlines
- Bureaucracy and paperwork
 - Liaison between Department of Health and Sites

Did you need to provide more support to sites at specific points in the programme? If so, which parts of the process did sites require most support with?

How **different** did you feel the Demonstrator Site programme was from previous initiatives which sites were delivering?

- Types of services offered
- Partnership arrangements
- Types of carers being targeted

Question 3: CONNECTION WITH NATIONAL STRATEGY

How do you feel the Demonstrator Sites project related to the broader aims of the National Strategy for Carers (as outlined in June 2008 document '*Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own'*)?

- Improve carers' health and emotional well-being
- Improve carers' quality of life
- Recognise the contribution carers make
- Increase carers' choice and control
- Benefit carers' economic well-being

Question 4: ORGANISATIONAL IMPACT / STAFF RESPONSES

We would like to get your views on the way in which the Demonstrator Site project has impacted on the organisations running the sites.

- How has it affected the work that the organisations involved in the sites do?
- How has it affected the other carer's services offered by the organisations

How have the workloads of staff at the Demo sites organisations changed?

- monitoring / reporting to Expert Advisers / Department of Health / NET
- assessing carers' needs
- arranging breaks for carers
- signposting carers

How well did you feel that the sites you were responsible for monitoring the throughput of carers on their services?

Question 5: BUDGET

How well do you feel that the budgetary arrangements worked for the Sites? Where there any difficulties / problems?

How much negotiation of budgets had to be done with sites at year end 1 / year end 2 / during the programme?

What was your role in monitoring the financial information?

- What level of input from yourself?
- What level of input from the Department of Health?

Was there, to your knowledge, any evidence of **cost shunting** regarding other local carer provision in any of your sites? Can you provide an example of this?

Question 6: RELATIONSHIPS BETWEEN SITES, DEPARTMENT OF HEALTH and EXPERT ADVISERS

How much direct contact did you have with your sites? Did this vary from site to site?

Did this vary from site to site?

Did you have more face to face contact with some sites than others and if so why? How did your **relationship** with the sites **develop** during the project? Did you have more or less

involvement over time? How did the type of involvement change?

What **impact**, if any, did you feel that your role as Expert Adviser had on the **delivery** of the demonstrator site services? Examples?

Question 7: REACHING CARERS

In your opinion, what strategies adopted by the sites that you were working with were the most successful in terms of:

- Identifying and accessing target groups of carers
- Identifying and accessing 'hard-to-reach' carers
- Reaching out to more carers

PLEASE PROVIDE EXAMPLES

- Were any of the strategies particularly innovative in terms of targeting carers?
- Were there any less successful strategies in terms of what targeting carers?
- How were the less successful ones dealt with by:
 - the site themselves?
 - o by the DH,
 - by you, the Expert Adviser?

Question 8: CARER INVOLVEMENT

How well did you think that the sites you worked with **included carers** in the design and delivery of their Demonstrator Site services?

- How were carers included?
- What were the benefits of including carers?
- Where there any disadvantages?

Question 9: BENEFITS

What do you see as the main benefits of the Demonstrator Site ...

- For CARERS (now and in the future)
 - Better health for carers
 - Better support for carers
 - Maintain and sustain caring roles
 - Improve relationship with family / cared for
 - Access to employment / training
 - More choice and control
- For THE SITES THEMSELVES (now and in the future)
 - Less social care needs for carers
 - o Better supported carers
 - Links with new partners
 - For the HEALTH AND SOCIAL CARE SYSTEM? (now and in the future)
 - Healthier carers
 - Promotion of carers' rights
 - Fewer emergency care / residential care admissions due to carer fatigue
 - Improving identification of carers / raising awareness of carer issues
 - o Increased engagement with voluntary and carer organisations
 - Identifying gaps in carer service provision
 - Improving systems and processes

PLEASE PROVIDE **SPECIFIC EXAMPLES** OF BENEFITS WHICH CAN BE **ATTRIBUTED** IF POSSIBLE

Were there been any limitations in the Demonstrator Site design and delivery?

- For CARERS
- For SITES
- For the HEALTH AND SOCIAL CARE SYSTEM?

Question 10: LOCAL EVALUATION

How well do you feel that sites managed evaluating their own services through their local evaluations?

How well do you feel sites managed to collect evidence in terms of the cost savings or potential cost benefits of the Demonstrator Site services?

- What models did those sites that managed to do this use?
- What were the barriers for those sites unable to do this?

Question 11: SUSTAINABILITY

Are you aware of plans in the sites you worked with to sustain the Demonstrator Site services, beyond the timeframe of DHDS funding?

How realistic do you think these discussions / plans are?

- What will this depend on?
- Have the sites asked for your advice on this?

Question 12: FINAL QUESTIONS

To sum up - from your perspective, which aspects of the Demonstrator Site services

- Worked well?
- Did not work well?
- Were particularly innovative?

If you had the opportunity to start this project **again**, is there anything you would do, or would advise sites to do **differently**?

What have been your key learning points from the Demonstrator site services that you would like to be noted to impact future carer policy?

Do you have **any other comments** you would like to make?

Appendix B Summary of site activities: objectives, partnerships and target groups

This appendix provides short summaries of each of the 25 Demonstrator Sites, including:

- Activities undertaken (as collated by the national evaluation team).
- Each site's objectives (including any revised objectives as appropriate) drawn from the original bids and local evaluation reports).
- List of organisations involved in each DS partnership, with a summary of their role in service delivery (drawn from site project bids, other site documents, quarterly calls, case study interviews and local evaluation reports).
- A list of the target groups identified (if any) by each site (as mentioned in each site's bid).
- An indication of whether each site supplied a local evaluation report.

<u>Notes</u>

- All information is derived from information provided by sites.
- Number of carers engaged by each site are indicated in Chapter 4.
- Carers from Black, Asian and other ethnic minority groups are referred to in this appendix as 'BME carers', the term used by many sites in describing Black Minority Ethnic carers.

Demonstrator Site: Bath and North East Somerset Type: Carers' Breaks

Summary of activity

Carers accessed breaks by completing a membership form, which they could receive assistance with from a carer development worker. To be eligible for a break, carers needed to be over 19 years old and to live in, or care for someone living in, the locality. After sending back the form, they were issued with a membership number and a letter explaining what to do / how to access breaks. They could then book a break through a brokerage officer. Carers could select a break from a programme of events / courses which were offered free to members by voluntary sector organisations and the lead partner. Providers were chosen based on what carers said they would like (in focus groups) although carers could also make individual break choices. Breaks were generally offered for a course / activity lasting no more than six weeks and could have a maximum value of £400 per carer. 'Carer days' were also held to raise interest in the different services offered, and gather feedback on carers' experiences of the DS services.

Objectives of the Bath and North East Somerset partnership

The Give Us a Break continues to work towards supporting and empowering carers and providing carers with:

-A social activity.

-Peer support / networking with other carers.

-Practical help e.g. replacement care to ensure the cared for person is safe and looked after during the break, ensuring a guilt free time away.

-Or activities which can involve both the carer and the cared for person together, with appropriate cover, if that is what both parties prefer.

-Other interests other than caring (important while the carer is caring, but equally important when the carer stops caring).

-Enhanced skills which can be used in caring, as self-development, or as preparation for work.

The outcomes sought from the project are:

-To enable carers to live a life of their own through a range of short breaks that interest them, suit their lifestyle and fit with their future goals.

-To improve carers' self-reported physical and mental health and well-being through opportunities for active leisure, creative leisure, music, arts therapy, and learning.

-To remove the barriers faced by carers preventing them accessing the opportunities provided by this service.

Methods used to engage carers in the services offered			
Posters / leaflets.			
Advertisements in local media (radio, newspapers).	\checkmark		
Outreach in local communities through providers / partner organisations.			
Television advertisements / promotional DVDs.			
Recruitment through GP practices.	\checkmark		
Events and road shows.			
Mail outs to carers / cared for persons.	\checkmark		
Websites.	\checkmark		
Other	\checkmark		

Members of partnership					
Lead partner Role / Description					
Bath and North East Somerset Council and NHS Bath and North East Somerset	Submitted a joint bid and the project was operated jointly by this partnership. The lead partners were involved in delivery. They also employed a brokerage officer who collected carer data and organised breaks.				
Other partners					
Bath and NE Somerset Council (Sports and active leisure services, heritage and library services, community learning services)	Involved in delivery of breaks.				
Soundwell Music Therapy	Delivered breaks.				
Learning Partnership Bath City College and Norton Radstock College	Delivered breaks.				
North East Somerset Arts (NESA)	Delivered breaks.				
Community Art Therapies	Delivered breaks.				
Off the Record	Delivered breaks to young adult cares.				

Target groups mentioned in the site bid				
Carers of people with mental ill-health.				
Rurally isolated carers.				
Young carers.				
BME carers.				
Disabled carers				

Local evaluation report received by NET	Produced internally / externally
Yes	Internal

Demonstrator Site: Bristol Type: Carers' Breaks

Summary of activity

Personalised breaks were delivered via two pathways: 1) assessments carried out by a project support officer or one of the voluntary organisations; 2) a health check involving a half hour session with a clinician, after which a break was prescribed. Breaks were offered in nine health centres and were usually organised by giving carers a direct one-off payment for the activity of their choice, which were very diverse. Another aspect of delivery was a 'whole family service' which took a holistic approach to working with 12 families (each including an adult and a child with physical / mental disabilities). In such instances carers were normally allocated to separate agencies, however, this service trialled supporting the parent and child together. This generally involved support that gave families more time to spend together.

Objectives of the Bristol partnership

-To develop a model of a Breaks-facilitator service in partnership with local voluntary organisations, Bristol City Council adult and children's social services departments.

-To develop and purchase on an ad hoc basis breaks assessments and brokerage services from local voluntary organisations.

-To provide an internal breaks assessment and brokerage service within Bristol City Council Health Social Care, receiving referrals from a variety of sources.

-To commission a breaks assessment, brokerage and development service from one voluntary organisation.

-Set up a partnership contract with a care provider to develop a model of flexible, whole-family delivery.

-Set up Health Checks for carers in at least 6 GP practices throughout pilot area.

Develop links to Occupational Therapy and housing services through all the local project gateways, to identify and evaluate ways in which those services can support flexible approaches to breaks.

-Set up a budget which is formally pooled between NHS Bristol, adult and children's services to support whole-family working.

-Hold bi-monthly Learning and Development meetings to include stakeholder representatives from all partners – sharing and developing learning and models.

Methods used to engage carers in the services offered			
Posters / leaflets.	\checkmark		
Advertisements in local media (radio, newspapers).	\checkmark		
Outreach in local communities through providers / partner organisations.	\checkmark		
Television advertisements / promotional DVDs.			
Recruitment through GP practices.	\checkmark		
Events and road shows.			
Mail outs to carers / cared for persons.			
Websites.			
Other.			

Members of partnership		
Lead partner	Role / Description	
Bristol City Council	The lead organisation, providing project management and carrying out the evaluation.	
	Adult Community Care delivered services.	
	<i>Children and Young Persons Services</i> delivered services and carried out work relating to young carers / parents. Also had a role in care provider development.	
Other partners		
NHS Bristol	Provided access to GP clinics who could provide breaks by prescription – a carer could have a health check with a clinician and be prescribed a break.	
Barnardo's	Were commissioned to deliver the 'whole family' service (following a tendering process).	
ReThink	Were commissioned to deliver the breaks facilitator service (following a tendering process) with a focus on the Bristol Somali population and mental health carers.	
Bristol Black Carers	Were paid on an ad hoc basis for assessing and finding carers. They focused on reaching BME carers and were involved in conducted breaks assessments.	
Bristol and Avon Chinese Women's Group	Were paid on an ad hoc basis for assessing and finding carers. They were involved in reaching and supporting Chinese carers.	
Dhek Bhal	An organisation that specialises in supporting people from Asian / Indian / Pakistani backgrounds. They were paid on an ad hoc basis for assessing and finding carers.	
Princess Royal Trust Carers' Centre	Were paid on an ad hoc basis for assessing and finding carers. They have engaged with carers and conducted breaks assessments.	

Parent carers.

Young carers.

BME carers.

Carers in areas of high health inequalities.

	Local evaluation report received by NET	Produced internally / externally
No		NA

Demonstrator Site: Derby	Type: Carers' Breaks	
Summary of activity		
This project involved several strands of delivery: The f and support service' – a telephone helpline (and webs and assistance around accessing short breaks. This accessing social services, information, advice and se services to widen breaks options / reduce stress. This inv care; a holiday placement scheme for older adults; pers free stress buster and creativity events; a life-style bene befriending / sitting service for carers (linked to the loc carers' information and advice network. This consisted information and support to carers, including help with ca and assistance with claim forms, information on resp support. Workers based here were also involved in dro fourth strand was a community enterprise supporting a surveys of carers and assist with carers' focus grou engagement, with a 'Carers as Ambassadors' scheme support and training to participate in planning and co-pro to help with dissemination of information to the public an Information and Advice Service' – this operated from O settings. Information about carers' breaks and other sup with support for using carers' self assessment process.	ite option) to provide carers with information also provided a single point of contact for lf-assessment. The second strand provided volved providing more flexible day and respite sonal budgets for carers; a free telecare trial; fits carers' discount scheme; and a dementia cal dementia strategy). A third strand was a I of information and advice workers offering arers' self assessment forms, benefits advice ite and signposting to further services and op in services at GP practices and clinics. A and training carers / ex-carers to undertake ps. The fifth delivery strand involved carer e which provided carers and ex-carers with oduction activities with statutory agencies and d other carers. The final strand was a 'Carers GP practices, clinics, pharmacies, community	

Objectives of the Derby partnership

-To establish the 'Carers Breaks Information and Support Service' including a website enquiry service. The system will be available for direct access by carers, and for access by GP's and other health professionals, and by voluntary sector organisations supporting carers.

-To widen the range of carers breaks options in conjunction with NHS Derby City and to improve access arrangements. New services will aim to reduce stress amongst carers and improve health. If required, help will be provided to enable joint attendance by the carer and the cared for person.

-To establish a new 'Carers Information and Advice Service' that will operate from GP practices and health centres. The service will provide information about carers' breaks and other support services to carers, particularly hard to reach carers and those not normally in touch with key support services. The service will include a new 'barefoot' information service to be offered by trained local carers and ex carers working as volunteers.

-To establish a community enterprise that will enable carers and ex-carers (with training and support) to undertake surveys of the carers accessing the breaks project, so that carers' experiences and views can help measure project outcomes.

Methods used to engage carers in the services offered	
Posters / leaflets.	
Advertisements in local media (radio, newspapers).	\checkmark
Outreach in local communities through providers / partner organisations.	
Television advertisements / promotional DVDs.	
Recruitment through GP practices.	√
Events and road shows.	
Mail outs to carers / cared for persons.	
Websites.	
Other.	\checkmark

Members of partnership		
Lead partner	Role / Description	
Derby City Council	Carried out project management and service delivery plus: co-ordination and oversight of contributions by partners; governance (through Elected Member representation on Derby Carers Strategy Partnership Board); co-ordination of Network of Carers Information and Advice providers operating at GP practices; involvement in service delivery for many aspects of the project.	
Other partners		
NHS Derby City (PCT)	Involved in project governance and were members of the project team. Promoted carers' issues with GPs and primary care staff, supported engagement and co-production activities, promoted the carers' self-assessment process, supported Network of Carers Information and Advice providers (NCIAP) operating at GP practices. Also worked with GPs to promote the take up of GPs carers registers and referrals to Carers Breaks Information and Support service.	
Age UK Derby and Derbyshire	Were involved in project governance, delivery of information and advice to carers (as a member of NCIAP operating at GP practices) and issued carers' self-assessment forms.	
Alzheimer's Society	Were members of the project team and delivered befriending service to carers of people with dementia.	
Crossroads	Delivered stressbuster sessions and provided a sitting service to carers' breaks.	
Derbyshire Carers Association	Main organisation working with carers, and involved in project governance. Delivered information and advice to carers (as a member of NCIAP operating at GP practices). They issued carer self assessment forms and worked with / trained carer researchers and ambassadors.	
Derby and South Derbyshire Mental Health Carers Forum	Were involved in governance (through membership of Derby Carers Strategy Partnership Board).	
Community Action Derby	Initial worked to set up carers engagement forum.	
Derby and Derbyshire Race Equality Council	Delivered information and advice to carers (also were member of NCIAP operating at GP practices). Issued carers self assessment forms.	
Derby Hospitals NHS Foundation Trust	Were involved in project governance (through membership of Derby Carers Strategy Partnership Board).	
Derbyshire Mental Health Services NHS Trust	Were involved in project governance (through membership of Derby Carers Strategy Partnership Board).	
Disability Direct	Delivered information and advice to carers (as a member of NCIAP operating at GP practices). Issued carers self assessment forms.	
Headway	Delivered information and advice to carers (as a member of NCIAP operating at GP practices). Issued carers self assessment forms.	
Making Space	Involved through membership of project team.	

Target groups mentioned in the site bid

Carers of people with dementia.

Local evaluation report received by NET	Produced internally / externally
Yes	Internal

Demonstrator Site: East Sussex Type: Carers' Breaks

Summary of activity

This project involved working closely with carers of people with mental health problems / dementia to provide short breaks, with breaks for carers facilitated by the provision of alternative care. East Sussex delivered Breaks by linking people together and forming groups working on a 1-4 staffing ratio with each case receiving initial 1-1 for engagement or on going 1-1 based on individual need. The site aimed to move away from traditional respite / day care services, with community support workers working closely with the cared for person to engage them in meaningful activities. This enabled the carer to take a break and reassured them that their cared for person was being well looked after. Activities could include one-to-one support for cared for and / or their carer out in the community, or group activities (including exercise, dance, entertainment, art therapies). The project also supported carers having a carer's assessment, and linked carers to carer-led groups and support networks.

Objectives of the East Sussex partnership

-To offer support from a community support worker (CSW) on a 1:1 basis in the carer's home and to agree with carers an action plan to enable the carer to benefit from regular short respite breaks.

-To support around 80 carers' planned breaks each quarter in each of the four areas

-For CSWs to befriend carers and enable them to benefit from other support available such as 'Caring and Coping' courses.

-To offer practical support to carers e.g. offering transportation to medical appointments and supervising the cared for person at the surgery / venue in order to minimise 'separation anxiety'.

-To offer advice, information and education about mental health / dementia and signpost to other services.

-To assist the cared-for person to engage in mainstream community activities (thus providing the carer with a respite break) where possible and to withdraw when confidence has been established.

-To assist and train those leading the activities to understand the specific needs around the mental health condition / dementia of the cared-for person.

-To support carers through a carers' support group facilitated by a resource officer and managed by carers - and to run in parallel with an activity for the cared-for person (e.g. coffee-club).

-To assist carers in completing assessments / reviews.

-To work effectively in partnership with relevant statutory and non-statutory groups and services.

The overall aim of these objectives is to deliver the following outcomes:

-To positively impact the health and well-being of carers and those they care for (including those who are currently 'under-reached') both during the immediate intervention and over the longer term.

-To prevent carer breakdown and thus reduce the demand on intensive health and social care services such as premature placement in residential care and reactive, emergency interventions. -For carers to be effectively included as 'partners in care'.

Methods used to engage carers in the services offered		
Posters / leaflets.		
Advertisements in local media (radio, newspapers).		
Outreach in local communities through providers / partner organisations.	\checkmark	
Television advertisements / promotional DVDs.		
Recruitment through GP surgeries.		
Events and road shows.		
Mail outs to carers / cared for persons.		
Websites.		
Other		

Members of partnership		
Lead Partner	Role / Description	
East Sussex County Council (Adult Social Care / mental health)	Provided a project management role and employed a team of CSWs and resource officers.	
Other Partner		
Sussex Partnership NHS Foundation Trust	Older People's Community Mental Health Team - referred carers to the breaks project. Provided office space, stationary and clinical supervision for the CSWs.	
Brighton University	Conducted the local evaluation	
Alzheimer's society	Worked alongside the project in providing support to people with dementia and their carers. Ran four of the carer groups and provided carers with training and support.	
Age UK	Provided five day centres around the county that worked with the project. Carers have also signed up as volunteers in these centres.	
Crossroads	Worked alongside the project to provide breaks for carers.	
A1	Local care agency who were trained by the CSWs to look after people with dementia.	
Various local community organisations and business (unofficial partners)	The project worked with various local community organisations to provide breaks for carers / activities for the person cared for (e.g. Glyndebourne Opera House, local schools, local worship groups, Parkinson's society, local police, fire and rescue, Abbeyfield Housing Society, Royal British Legion, WRVS).	

Target groups mentioned in the site bid		
Carers of people with mental ill health.		
Carers of people with dementia.		
LGBT carers.		
Rurally isolated carers.		
BME carers.		
Carers in areas of deprivation.		

	Local evaluation report received by NET	Produced internally / externally
Yes		External, by University of Brighton

Demonstrator Site: Hertfordshire Type: Carers' Breaks

Summary of activity

'Book your own breaks' service was an online booking system through which carers could book respite care with a care worker, and at a time, of their choice. The carer's details were sent to the chosen care worker who was vetted by Crossroads care. There was also a volunteer service delivered by Breakaway added to the project, in which volunteers provided cover (or sitting services), although not direct care. This was also added to the online system. There were two coordinators employed full time on the project, who worked at getting referrals on the system through training carer support workers, making bookings, and delivering promotional presentations in the locality.

Objectives of the Hertfordshire partnership

-Raise awareness about Book Your Own Breaks among carers, local carer groups, social workers and other organisations such as Job Centre Plus.

-Expand the marketplace across the County in a progressive and sustainable manner.

-Grow the marketplace so that 350 carers and 100 care support workers are registered by March 2011. These users may be using either a paid for or voluntary service.

-Continually model the marketplace to ensure an increasing number of carer breaks are booked month on month. These are monitored against clear targets agreed by the steering group.

-Provide training materials for the marketplace. These include a manual and a video demonstration.

-Assist carers to use the marketplace independently.

-Encourage self funders to be part of the marketplace.

-Gain feedback from users so we can develop the marketplace to make it more useful for carers.

-Enable Hertfordshire to have transparency around the bookings. Information that will be easily available includes cost, patterns of demand for care support workers and amount spent against budget per carer.

-Encourage carers who can self manage to do so therefore reducing the cost to the council of looking after carers.

-Determine how to create a sustainable marketplace.

Methods used to engage carers in the services offered		
Posters / leaflets.	\checkmark	
Advertisements in local media (radio, newspapers).	\checkmark	
Outreach in local communities through providers / partner organisations.	\checkmark	
Television advertisements / promotional DVDs.		
Recruitment through GP practices.	\checkmark	
Events and road shows.		
Mail outs to carers / cared for persons.		
Websites.	\checkmark	
Other.	\checkmark	

Members of partnership		
Lead partner	Role / Description	
Hertfordshire County Council	Managed and oversaw the project.	
(Adult Community Services)		
Other partners		
Slivers of Time	Carried out the main delivery of the project and created the online break booking service.	
Crossroad Care Hertfordshire North	Was a provider commissioned as part of the DS project. They provided the respite care that was booked online, providing care service workers who had been CRB checked. These service workers were paid by Crossroads.	
Crossroad Care Hertfordshire South	Was a provider commissioned as part of the DS project. They provided the respite care that was booked online, providing care service workers who had been CRB checked. These service workers were paid by Crossroads.	
West Hertfordshire Hospitals NHS Trust (commissioning)	Provided funding and functioned in an advisory role.	
Breakaway	Provided volunteers to cover for carers (e.g. sitting services, but not care).	

Target groups mentioned in the site bid	
Carers of people with mental ill-health.	
Carers of people with learning disabilities.	
Carers of people with physical disabilities.	
Older carers.	
BME carers.	
Self-funding carers.	

Local evaluation report received by NET	Produced internally / externally
Yes	Internal

Demonstrator Site: Lewisham Type: Carers' Breaks

Summary of activity

This site explored new ways of delivering breaks and self assessments to carers, delivered via the local authority (Community Services). It had three comparator groups of carers receiving different forms of breaks: group 1 received a one-off direct payment for a break of the carers' choice; group 2 received ongoing direct payments to fund sitting services or domestic support; group 3 received traditional carers' services – e.g. sitting, or domestic support. The site focused on carers of people with dementia. The service was delivered by social workers, who conducted the carer's assessments and then supported carers in developing support plans and accessing personal budgets or other services. Personal budgets were issued either via a direct payments scheme or were commissioned by the council.

In practice, however, the Carers' Breaks project needed to remain flexible to take account of carer needs and thus a decision was made to encompass traditional services. During the set up of the Carers' Breaks project, feedback from carers indicated that it should continue to allow carers in the DS project to access purchasing and provision via the council. Therefore carers had an option to access services in the traditional way or get independent funding or a mix of the two.

The site carried out additional work on training and support planning, and there was an increase in activity.

Objectives of the Lewisham partnership

-To evaluate and compare new approaches to self assessment and breaks for carers by trying to assess 150 carers and organise a carers support plan for 100 carers. They will also interview 20 carers using in-house respite services (therefore not accessing the pilot) to compare service satisfaction with carers on the pilot.

-Ensure that BME carers are fully engaged in the process and their specific cultural needs are taken into account.

-Facilitate action-learning sets with carers to promote innovation and learning.

-Identify whether any new short break services should be commissioned and whether any traditional services should be de-commissioned.

-Encourage partners to evaluate the impact of new break services on the well-being of the person cared for as part of the implementation of the local dementia strategy.

-Institute a monthly pilot project board that monitors, implements the project plan, and monitors the project risk assessment. Decision making power will sit with the pilot project board.

Methods used to engage carers in the services offered	
Posters / leaflets.	\checkmark
Advertisements in local media (radio, newspapers).	\checkmark
Outreach in local communities through providers / partner organisations.	
Television advertisements / promotional DVDs.	
Recruitment through GP practices.	
Events and road shows.	\checkmark
Mail outs to carers / cared for persons.	
Websites.	
Other.	

Members of partnership	
Lead partner	Role / Description
Lewisham Council (Community Services)	Performed a management role. Was also involved in delivery and the local evaluation.
Other partners	
Lewisham PCT (Commissioning)	Made referrals to the project. The 'Carers Lead' attended the pilot project meeting to ensure there was synergy between services and commitment to implement the project plan milestones.
South London and Mausley Mental Health Trust (SLAM) (Older Adult Mental Health Team)	Made referrals to the project and had a role in project governance via the project board (SSI grid). Liaised closely in relation to the implementation of the Lewisham Dementia Strategy.
Carers Lewisham	Involved with the project in an advisory capacity, working closely with the pilot project group and the project manager organising the carers' reference group. The Carers Lewisham manager attended monthly pilot project meetings and had a role in implementing the project plan.
Alzheimer's Society	Involved with the project in an advisory capacity

Target groups mentioned in the site bid	
Carers of people with dementia.	
BME carers.	

	Local evaluation report received by NET	Produced internally / externally
Yes		External, by Define Research and Insight Ltd

Demonstrator Site: Liverpool Type: Carers' Breaks

Summary of activity

This project supported carers to receive personalised breaks. Carers could receive a Carers Personal Budget (CPB) for up to £600 to support them to take a break and to help alleviate some of the stresses that can arise when caring for someone. Carers could be referred for a CPB either by self referral or via a professional body contacting the Demonstrator Site project team. An initial contact form was completed by the project team, and the carer was then sent an information pack and self-assessment form to complete (unless one had already been completed by the social worker). Once this form had been completed, the carer was allocated to a self directed support planner, who would make an appointment with the carer to complete their Carer Support Plan while taking time to listen to carers needs and explore how they wanted to spend their budget and whether additional services might be needed. The Carer Support Plan would then go to a panel, whose members discussed it and made a decision around the allocation of a break. Breaks were 'whatever the carer thinks is a break', and included a range of diverse activities: day trips, holistic therapies, longer holidays / family holidays, fishing equipment, bike, lap tops, and gym memberships.

Objectives of the Liverpool partnership

-To provide individual, personalised breaks for carers, which have been identified through a person centric support planning process.

-To develop a process that is flexible and reactive to individuals needs and will enable a bespoke break for carers and families linked to self identified outcomes providing carers the opportunity to exercise choice and control when determining the type of support they want.

-To effect a whole system change to ensure a carer-focused culture is embedded.

-To create a policy and process underpinned by the principles of personalisation and citizenship.

-To deliver a project that is accessible to all carers including those traditionally under reached.

-To readdress existing inequities across client and community groups through the use of self directed support driven by carers' individual needs and requirements.

-To develop a self (supported) assessment and support plan document.

-To map and expand universal mainstream provision to enable and facilitate informed choices.

-To ensure evaluation based on carers experiences.

-To achieve organisational learning through the evaluation process that will inform and develop future policy and strategy.

Methods used to engage carers in the services offered	
Posters / leaflets.	\checkmark
Advertisements in local media (radio, newspapers).	
Outreach in local communities through providers / partner organisations.	
Television advertisements / promotional DVDs.	
Recruitment through GP practices.	\checkmark
Events and road shows.	
Mail outs to carers / cared for persons.	
Websites.	
Other.	\checkmark

Members of partnership		
Lead partner	Role / Description	
Liverpool City Council (Children, Families and Adult Social Services)	Held a management role and oversaw the project. Provided Personal Budgets for carers to spend on breaks of their choice.	
Other partners		
Liverpool PCT	Stakeholder Engagement, Integrated Commissioning were involved in the project in an advisory capacity.	
	Mersey care members were on the steering group.	
	<i>GP</i> s a separate pilot was run involving GPs. They automatically recorded if carers they have contact with are already known to GPs.	
Barnado's	Involved in the project in an advisory capacity.	
Tourist Board	Involved in delivery and offered a breaks brokerage role if necessary.	

Target groups mentioned in the site bid

BME carers.

Local evaluation report received by NET	Produced internally / externally
Yes (draft report)	Internal

Demonstrator Site: Nottinghamshire Type: Carers' Breaks

Summary of activity

This site sought to deliver and explore effective models of providing personalised breaks to carers. In doing this the site identified three key themes: emergency respite care; dementia services; and joint breaks. Breaks and support services around these key areas were provided by seven third sector partnership organisations. These included two organisations providing emergency or crisis prevention breaks, one providing a dementia day care activity based service, three organisations providing single or joint (the carer and cared for together) breaks and two organisations engaging with Gypsy and Traveller carers and ethnic minority carers respectively. In addition, a new service was commissioned which was funded entirely by NHS Nottinghamshire County to provide carer support and breaks for those caring for patients Nearing End of Life.

Objectives of the Nottinghamshire partnership

Within first 6 months:

-To evaluate the quality of existing breaks' services, understand which of these are valued by carers and why, and what carers do not find beneficial and why.

-To understand why specific groups of people are not accessing existing breaks' services and to identify what support our local community groups need to enable carers to access and benefit from local support within their communities.

Within 18 months:

-To gain evidence and understanding of how volunteering improves the quality of life of carers and how carers may be supported to gain employment.

-To understand what the demand may be for joint breaks for the carer, the person they care for, and their family.

-To have developed services which provide individually tailored breaks.

By the end of 2 years:

-To understand the cost of different types of breaks' services.

-To have some new initiatives tried and tested and evaluated which can be developed as longer term provision.

-To have developed skills and expertise on evaluating the effectiveness of breaks on carers and their families.

Methods used to engage carers in the services offered	
Posters / leaflets.	\checkmark
Advertisements in local media (radio, newspapers).	\checkmark
Outreach in local communities through providers / partner organisations.	
Television advertisements / promotional DVDs.	
Recruitment through GP practices.	\checkmark
Events and road shows.	\checkmark
Mail outs to carers / cared for persons.	
Websites.	\checkmark
Other.	

Members of partnership	
Lead partner	Role / Description
Nottinghamshire County Council (Adult Social Care and Health)	Managed and oversaw project. Chaired the project board.
Other partners	
NHS Nottinghamshire County	The commissioning lead for carers of people near the end of life (NEOL) and people with dementia. Also delivered the near end of life project 'Pathways Carer Support'.
Age Concern	A co-ordinator used a team of volunteers to provide regular breaks to carers. This included individual breaks for the carer (for which a sitting service was provided) or a joint break for the carer and cared for together.
Care and Comfort	Provided a befriending and carers support service with an emphasis on personalising breaks.
North Notts Crossroads Carers	Provided day time support and leisure activities in Bassetlaw, Newark and Sherwood districts.
East Midlands Crossroads	Provided unplanned breaks due to emergency / crisis situations in the south of the county.
Headway	Provided joint holiday breaks and individual breaks to carers / service users with head injuries.
Rushcliffe CVS	Had a role raising awareness of breaks services. Appointed a BME Support Worker who engaged with ethnic minority carers and encouraged them to take up personalised breaks
Newark and Sherwood CVS	Had a role in raising awareness of breaks services within Gypsy and Traveller communities. A Traveller health worker providing personalised breaks.
University of Nottingham	Assisted with the local evaluation.

Target groups mentioned in the site bid

Carers of people with dementia.

Carers of people with learning disabilities.

Carers of people with physical disabilities.

Rurally isolated carers.

BME carers.

Gypsy and Traveller carers.

Complex conditions other than those specified.

	Local evaluation report received by NET	Produced internally / externally
Yes		External, by University of Nottingham
Demonstrator Site: Suffolk Type: Carers' Breaks

Summary of activity

There were two main aspects of the project: the first, called Time For You, involved funding family carers to access personalised breaks. This was delivered in two stages: stage one involved recruiting 300 hidden / under-reached family carers and also gathering information on finding family carers, what carers want, the impact of the initial direct payment, and how the project has impacted upon organisations employing family carers; stage 2 involved using the information from stage 1 to develop new and innovative short breaks. The second aspect of the project was the Time For Carers website, which enabled family carers to access information and make booking requests for available breaks. It also enabled providers of family carer services and breaks, as well as businesses providing concessions to family carers, to publicise their services.

Objectives of the Suffolk partnership

-To set a target number of previously hidden carers to be identified within each part of the project.

-To pilot alternative approaches that will increase the uptake and improve the flexibility of respite for individuals from disadvantaged and BME Communities.

-To effectively engage family carers, in particular those carers that are under-represented in current service provision, and seek their views about ways that support can be designed to meet their needs.

-To identify new approaches in respite care that improves health and well-being outcomes for carers and those they care for.

-To develop an evaluation and quality assurance framework that provides a robust baseline and evidence base for future service provision.

-To develop effective innovative models of delivering respite care that can be replicated in future service commissioning.

-To use Patient Reported Outcome Measures to measure perceived improvement in quality of life for carers and the impact of different types of breaks.

-To develop proven processes and approaches of engaging and supporting parent carers from harder to reach groups.

-Establish more effective and efficient systems, and provide accessible information and approaches to identify and engage young carers from harder to reach groups, which will also inform County strategy developments.

-To develop a website for family carers – Time for Carers – using and enhancing technology used within the previously existing Activities Unlimited website.

Methods used to engage carers in the services offered	
Posters / leaflets.	\checkmark
Advertisements in local media (radio, newspapers).	\checkmark
Outreach in local communities through providers / partner organisations. $$	
Television advertisements / promotional DVDs.	
Recruitment through GP practices.	
Events and road shows.	
Mail outs to carers / cared for persons.	
Websites.	\checkmark
Other.	

Members of partnership	
Lead partner	Role / Description
Suffolk County Council (lead organisation)	Provided overall management.
Other partners	
Suffolk Family Carers	A strategic partner in relation to family carers. Recruited carers by sending out adverts to contacts and they also received referrals for support, project board / steering group involvement.
	They were commissioned to provide appropriate training and support to the researchers, champions and community development workers and carers that became involved in the project.
	They provided training and expert advice to community development officers
NHS Suffolk	Had limited involvement in commissioning and the advisory board.
Ipswich Borough Council	Were involved in delivery, also recruited hidden / under-reached family carers in partnership with the Bangladeshi support centre.
Turning Point (Connected Care)	Were involved in stage one of the project, recruited and trained family carers as researchers. Were also involved in delivery / recruitment in Brandon
Activities Unlimited	Were involved in setting up the website.
Family Carers Partnership Board	This group aims to represent family carers needs and is made up of a range of voluntary and statutory organisations and family carers. They were involved in an advisory and monitoring role.
Bangladeshi Support Centre (BSC)	A voluntary sector organisation that worked in partnership with Ipswich Borough Council to recruit hidden / under-reached family carers in BME communities in Ipswich
Suffolk Acre	Involved in stage one and two of the project in Peasenhall / Sibton and in stage two of the project in the Brandon area.

Target groups mentioned in the site bid

Carers of people with dementia.

Carers of people with learning disabilities.

LGBT carers.

Young carers.

BME carers.

Carers in areas of deprivation.

Local evaluation report received by NET	Produced internally / externally
Yes	Internal

Demonstrator Site: Sunderland Type: Carers' Breaks

Summary of activity

Sunderland provided personalised breaks and development opportunities for carers, which could be accessed without going through local authority assessments. Carers could apply to a multi-agency consortium to access their break. During application they would specify the type of break / opportunity they would like to access and how the break would benefit them. When carers were referred to the project, they could make an appointment with a Carers Development Worker, either at their own home or at the carers' centre, to receive support in the process of applying for a break and choosing the right type. Carer Development Workers also signposted carers to other services and support. The consortium acted as a decision making panel for the allocation of the break / opportunity, and once it approved the break application the carers' centre administered the transfer of money to the carer. A maximum of £500 was allocated for breaks, although there was no limit on the number of times the carer could apply for a break. Types of breaks included: driving lessons; hang-gliding lessons; Wii-fit; alternative therapies; beauty treatments; gym membership; pampering sessions; physiotherapy; a wild-life park pass; and group breaks. Sunderland also placed an emphasis on development opportunities such as educational courses and training.

Objectives of the Sunderland partnership

The aim of the Sunderland carers break project was to improve the quality of life of carers through providing personalised breaks to enable all adult carers to access opportunities outside of their caring role and to lead a fulfilling life. The project was delivered in partnership between Sunderland City Council, Sunderland Teaching Primary Care Trust and Sunderland Carers' Centre.

Methods used to engage carers in the services offered	
Posters / leaflets.	\checkmark
Advertisements in local media (radio, newspapers).	\checkmark
Outreach in local communities through providers / partner organisations.	
Television advertisements / promotional DVDs.	
Recruitment through GP practices.	
Events and road shows. $$	
Mail outs to carers / cared for persons.	
Websites.	
Other.	

Members of partnership	
Lead partner	Role / Description
Sunderland City Council	Played a strategic commissioning role and provided overall management of the project. Employed one Carers Development Worker who worked with carers to choose breaks. They held the budget for breaks.
Other partners	
Sunderland Carers' Centre	Provided delivery and project management on behalf of Sunderland City Council. Employed two Carer Development Workers. Also received referrals from development workers for additional support.
South of Tyne and Wear NHS Trust (Sunderland PCT)	Held a commissioning role. Also provided services to deliver replacement health care. Also referred carers to the Carer Development Workers on the project.

Target groups mentioned in the site bid

No specific target groups.

Loca	al evaluation report received by NET	Produced internally / externally
Yes		Internal

Demonstrator Site: Torbay Type: Carers' Breaks

Summary of activity

There were four main strands or 'task groups' involved in this project:

Carers Breaks Plus - This was an enabling service provided by Crossroads Care supporting self assessment by assisting in the development and testing of a carers self assessment tool. The service provided independent brokerage, personalised carer support and community development. This service was available to all carers across the different work-streams.

Young Adult Carers - This strand aimed to explore effective ways of providing support and breaks for young carers. This included 'young adult carers development workers' working both one-to-one and in groups with young carers, and supporting their development in relation to education, employment and leisure / breaks. The project has also been working with local schools and colleges in identifying young carers, and a society for young carers was set up at the local college.

Older Family Carers - This strand involved: setting up a network of community support and promoting person centred planning; finding and supporting older family carers of adults with learning disability and helping them to access information; and supporting them through self-assessment and in accessing breaks. It also involved individual work with families, including using and developing 'life books', which helped families plan for the future.

Dementia - This strand aimed to support carers of people with dementia and improve pathways to support. It also included an adult placement scheme where hosts gave up their home to take care of someone with dementia to give the carer a break. Another element was the provision of memory cafes providing information, support and social networks to carers and people with dementia. In addition, through GP practices, health checks were provided for both carers and people cared for.

Other aspects of the project include various initiatives for carer involvement, a carer led website, and an online forum.

Objectives of the Torbay partnership

-The development of an independent enabling service offering supported self assessment and brokerage services for all groups of carers.

-Increase the number and range of carers getting tailored packages of breaks plus support for their own personal development, health and well being. (Target 393 carers)

-Evaluate the cost effectiveness of tailored Carers Breaks Plus. Make comparison of costs of specific breaks services arranged through the site (adult placement scheme for older people, flexible home based breaks, Older Family Carers Initiative) with traditional residential and day care provision.

-Develop specific tools for carers to plan their 'breaks' e.g. individual life plans / action plans, which includes a focus on their health and well being.

-Set up a collaborative partnership between primary care, the voluntary sector and statutory older peoples mental health services to identify hidden carers (not already known) of people with dementia and provide a pathway to develop a specific support service for young adult carers (aged 16-25).

-Establish routes for self funders, carers not willing to go through traditional assessment processes and carers in receipt of individual budgets to access information advice and breaks services.

-Set up local 'drop in' carers resources in three towns as bases for local community development and improvement in access to support for carers.

-To promote awareness of carers needs in local communities (ward level), particularly in the most deprived wards in Torbay, and establish new networks of carer support.

-To evaluate the impact on carers physical and mental health of the breaks and support services provided through the site and develop an evidence base to inform future commissioning.

-Engage carers in the planning, design and monitoring of the site and provide direct employment and self development opportunities for carers through the site activity.

-To develop a learning culture that provides educational opportunities for staff in local statutory and voluntary organisations and promotes reflective practice.

-To promote commissioning of established good practice models in breaks services through evaluating existing provision and recording the learning from new service development during the demonstrator site.

Members of partnership	
Lead partner	Role / Description
Torbay Care Trust	Had a role in commissioning and strategic governance. The provider arm had a role in delivery of the service.
Other partners	
St Luke's Medical Centre and Chelston Hall Surgery	Both GP practices had a role in referral, health support / signposting and delivering health checks. Were involved in the dementia work-stream.
Torbay Council	Children's Services and 'Supporting People' were involved in the young adult carers' service.
Crossroads Care	Were a provider for Carer Breaks Plus and also involved in providing the SWAPS scheme for the dementia work-stream.
Mencap	Carried out the Older Family Carers initiative, provided networks of community support and person centred planning.
COOL Recovery	Involved in the young adult carers strand.
Devon Partnership Trust	Involved in provision of services to young adult carers.
Alzheimers Society	Ran the Memory Café.
South Devon College	Involved in the young adult carers project strand and in development of Torbay Carers Forum.

Methods used to engage carers in the services offered	
Posters / leaflets.	\checkmark
Advertisements in local media (radio, newspapers).	\checkmark
Outreach in local communities through providers / partner organisations. $$	
Television advertisements / promotional DVDs.	
Recruitment through GP practices.	\checkmark
Events and road shows.	
Mail outs to carers / cared for persons.	
Websites.	
Other.	

Target groups mentioned in the site bid	
Carers of people with dementia.	
Older carers.	
Young carers.	
BME carers.	
Self-funding carers.	
Carers in areas of deprivation.	

Local evaluation report received by NET	Produced internally / externally
Yes (draft report received)	Internal, with aspects carried out by the University of Manchester

Demonstrator Site: Warwickshire Type: Carers' Breaks

Summary of activity

Warwickshire aimed to make support services, particularly breaks, more accessible to all carers through a web based portal. This enabled carers to book a range of breaks using personal budgets and / or their own resources. There was a facility to allow the carer to search, view and compare all available respite care providers in Warwickshire and to book services online. Carers were also able to rate or score providers. There was a large range of providers registered on the website, presenting carers with a full choice. A break was defined as a period of respite care, which could be for up to a week. In addition to an online break booking system, the website also functioned as an information resource and service directory for carers.

Objectives of the Warwickshire partnership

-To take advantage of the benefit of Warwickshire Adult Health and Community Services being a demonstrator site for the development of the Common Assessment Framework tool kit and develop a similar tool for carers. This will include an online self assessment for carers and a resource allocation system that determines carers' eligibility for adult social care support and the allocation of an individual budget for the carer to enable them to purchase their own support as and when they choose.

-To establish joint plans with health, and other partners, to increase the range of breaks available to carers through partners' procurement and contracting rules.

-To test the viable, legal and effectiveness of a customer facing on line web based system to record procured services available to carers.

-To build an online web based booking system to enable carers to book their breaks and other support services at times that fit within their own lifestyles, using their individual budget or own resources.

-Measure the reduction of the current levels of inequalities in health and social care outcomes for socially excluded people and communities in Warwickshire of using this approach to delivering support to carers.

-Identify and evaluate the cost benefits, including human resource efficiencies achieved through this approach.

-Test a range of methodologies that measure carer involvement throughout the levels and key stages of the design, implementation, monitoring of the demonstrator site, including the use of an instant feedback tool to capture feedback, including feedback from self funders.

-Evaluate the effectiveness of revised policies and procedures for frontline staff having particular interest in staff's own understanding of and cultural change in the way they work with and approach carers issues.

-Measure the positive and negative impact on the care market and any changes to the way services need to be commissioned.

Methods used to engage carers in the services offered	
Posters / leaflets.	
Advertisements in local media (radio, newspapers).	
Outreach in local communities through providers / partner organisations.	\checkmark
Television advertisements / promotional DVDs.	
Recruitment through GP practices.	
Events and road shows.	
Mail outs to carers / cared for persons.	
Websites.	\checkmark
Other.	\checkmark

Members of partnership	
Lead partner	Role / Description
Warwickshire County Council	Managed and oversaw the project. Were involved in delivery; social work teams advertised and promoted the breaks scheme. They also made
(Adult Health and Care Services)	sure that service users were aware of it and could use it.
Other partners	
NHS Warwickshire	Were involved in governance through the project board. Distributed publicity materials in GP practices.
NHS Choices	Were the main partner to Warwickshire County Council and were involved in technological development. They were involved in the project in various ways and had a role in the deciding the scope of delivery.
Slivers of time	They supported NHS choices in the development of the online tool. They went through a procurement process, and were subcontracted to NHS choices for the booking element.

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Carers of people with learning disabilities.

Local evaluation repo	ort received by NET	Produced internally / externally
Yes		Internal

Demonstrator Site: Camden Type: Health Checks

Summary of activity

Health and well-being checks for adults were provided by a carers' centre. The health checks were administered by clinical staff and included screening for blood pressure, cholesterol and testing carers' BMI. If anything requiring attention was identified by a health check, the carer was referred to their GP for further health support.

The well-being checks were provided by staff at the carers' centre, and involved a detailed interview examining the day to day caring situation (e.g. the number of hours spent caring and condition of the cared for person) and examined what well-being services were required. These could include services such as breaks, respite, or support activities such as help with shopping. Some services were provided to carers in-house at the carers' centre but if the carer needed something else such as a statutory service or assessment they were referred to the relevant outside agency.

There was also a young adult carers' strand to the service run by Crossroads Care Camden which focused upon well-being support. For this service health checks were not carried out (although the carers could be referred for health checks if needed). The well-being service involved identifying younger carers (16-25 years) and providing them with assistance in accessing counselling, education, training and employment, and signposting to other services for further support or development. The site are also ran residential trips for young carers, which involved life skills training, confidence building, communication, leadership, and self awareness training.

Objectives of the Camden partnership

-To improve or maintain the health and well-being of carers.

-To establish an effective methodology for identifying hidden carers.

-To refer carers to relevant specialist services as a result of the health and well-being check.

-To support volunteer carers to develop new transferable skills that can be utilised in future employment or education opportunities.

-To engage with hard to reach carers with emphasis on younger carers in the age range 16-25 years.

-To increase engagement of primary care in identification and support of carers.

Methods used to engage carers in the services offered		
Posters / leaflets.	\checkmark	
Advertisements in local media (radio, newspapers).		
Outreach in local communities through providers / partner organisations.	\checkmark	
Television advertisements / promotional DVDs.		
Recruitment through GP practices.	\checkmark	
Events and road shows.		
Mail outs to carers / cared for persons.		
Websites.		
Other.		

Members of partnership			
Lead partner	Role / Description		
London Borough of Camden	Provided a project management role and led on the evaluation.		
Other partners			
Camden Carers' Centre	Carried out delivery; provided well-being checks and primary care development work. Project delivery staff were based at the carers' centre. Worked with carer volunteers.		
NHS Camden	Provided the joint commissioner / project manager and clinical staff to carry out health checks.		
Crossroads Care, Camden	Delivered the young adult carers project.		
A network of more than 60 service units and organisations in Healthcare, well-being activities, voluntary sector advocacy and support, neighbourhood / community support, welfare, and housing. Including engagement with local GP practices and pharmacies.	These organisations had a role in identifying carers, signposting services, making referrals, and raising awareness of health checks among professionals and carers.		

Target groups mentioned in the site bid		
Carers of people with substance misuse problems.		
Carers of people with learning disabilities.		
Young carers.		
BME carers.		
Bereaved / NEOL carers.		
Self-funding carers.		
Carers in areas of deprivation.		
Carers in areas of high health inequalities.		

Local evaluation report received by NET	Produced internally / externally
Yes (draft report received)	Internal

Demonstrator Site: Devon Type: Health Checks

Summary of activity

This site carried out carer-directed health and well-being checks and follow-up annual reviews. Checks were delivered through pharmacies, GP practices, Complex Care Teams and by St John Ambulance. The site also held health checks for specific target groups, including centre-based checks for ethnic minority carers, and health events for young carers. GP practices were also involved, entering carers onto NHS recording systems. Additionally, a Peripatetic Nurse provided general carer checks and workplace checks.

Objectives of the Devon partnership

-To establish three "super sites" with choice of providers for carers within which they could study in some depth the local partnership issues. Within each there would be: GP practices acting as the central coordination point with project support workers setting up relevant systems and processes, helping to develop a whole practice approach to support carers, and increasingly providing carer support within GP practices. Alongside this are several groups of identifiers of carers: health and social care professionals, Carers Link and other voluntary sector staff, schools and other children's projects, pharmacists to assure targeting of hidden carers and carers of people with complex needs. Also there were those who would provide the checks: GP practices, pharmacists, St John Ambulance, health and social care teams.

-In addition to this: efforts were made to involve GP practices outside super sites (based on their voluntary participation), to support access to checks for ethnic minority carers and to provide workplace-based checks for working carers.

-Efforts were also to be made to identify an attractive approach for young carers to have checks.

-It was also planned to recruit pharmacies in key areas to respond to demand from carers who do not have access through their GP and to promote usage of mainstream health services to ethnic minority carers.

-The project aimed to deliver a minimum of 3,000 health / health and well-being checks, raise general awareness of carers, improve systems and processes and create a template for health and well-being checks.

Methods used to engage carers in the services offered		
Posters / leaflets.	\checkmark	
Advertisements in local media (radio, newspapers).	\checkmark	
Outreach in local communities through providers / partner organisations.	\checkmark	
Television advertisements / promotional DVDs.		
Recruitment through GP practices.	\checkmark	
Events and road shows.		
Mail outs to carers / cared for persons.		
Websites.	\checkmark	
Other.	\checkmark	

Local evaluation report received b	Produced internally / externally
Yes	Internal

Members of partnership			
Lead partner	Role / Description		
NHS Devon	The Joint Planning and Strategic Commissioning department was involved in management of the project and was a collaborator in the workplace checks initiative. The Public Health arm had an advisory role and a role in training. Exmouth and Budleigh Complex Care team had a role in delivery of the project.		
Other partners			
Devon Partnership NHS Trust	Had an advisory role.		
Northern Devon Healthcare Trust	Barnstaple Complex Care Team were involved in delivery.		
Devon County Council	The Joint Planning and Strategic Commissioning department was involved in management of the project and was a collaborator in the workplace checks initiative; Adult and Community Services (Older People / Older People and Physical Disability / Physical Disability) had a role in delivery; The Children's Trust identified and supported young carers; Learning Disability Partnership had a role identifying carers.		
Devon Local Pharmaceutical Committee	Support in relation to involvement of pharmacies.		
Devon Carers Forum	Governance.		
Devon St John Ambulance	Delivery.		
Sahara (outreach arm of Hikmat)	Identifying BME carers, delivery support, delivery.		
GP Practices	33 practices involved in delivery.		
Pharmacies	Delivery.		
University of Plymouth	Providing independent evaluation of Devon site.		
Devon Carers Link (Westbank)	Development partner and support to delivery.		
Devon Young Carers Consortium and Young Devon	Development and delivery partners.		

Target groups mentioned in the site bid
Carers of people with dementia.
Carers of people with a long-term condition.
Older carers.
Workforce carers.
Male carers.
LGBT carers.
Rurally isolated carers.
Parent carers.
Young carers.
BME carers.
Bereaved / NEOL carers.
Carers of people with sensory disabilities.
Complex conditions other than those specified.
Carer of people with HIV / AIDS.
Carers of people with aggressive or unsociable behaviour.

Demonstrator Site: Northumberland Type: Health Checks

Summary of activity

This site delivered health checks to carers in their own home or a location of their choice by district nurses / community nursing teams. The first part of the health check examined physical health including testing blood pressure, cholesterol, BMI, and then checks went on to examine wider social and environmental factors including: medications, family history, caring role, mental health, life-style, hospital admissions, and social support. Nurses also signposted and referred carers to further support. The project also focused on working with GP practices, with carer support workers based in six GP practices, whose role included raising awareness and conducting staff training.

Objectives of the Northumberland partnership

-Design an effective tool in partnership with carers, for the health checks that will extend to cover areas that impact upon the carer's well-being e.g. environmental, financial checks.

-Assess impact of the check in detecting health and well-being issues early and the measures taken to avoid deterioration in carer health.

-Assess impact effect of the checks on access to social care help and resulting improvements in health and well-being.

-Assess impact upon workforce alongside the benefits in sustaining the caring role to support future commissioning decisions and change practice.

-Assess impact of partnership working around carers' issues upon staff in primary care.

-Assess role of health checks and associated support in sustaining the caring role and avoiding crisis situations, admissions to secondary care or long term care for the cared for.

Methods used to engage carers in the services offered		
Posters / leaflets.	\checkmark	
Advertisements in local media (radio, newspapers).		
Outreach in local communities through providers / partner organisations.		
Television advertisements / promotional DVDs.		
Recruitment through GP practices.	\checkmark	
Events and road shows.	\checkmark	
Mail outs to carers / cared for persons.		
Websites.		
Other.	\checkmark	

Target groups mentioned in the site bid Carers of people with substance misuse problems.

Older carers.

Rurally isolated carers.

BME carers.

Complex conditions other than those specified.

	Local evaluation report received by NET	Produced internally / externally
Yes		Internal

Members of partnership		
Lead partner	Role / Description	
Northumberland Care Trust	An Integrated Trust – a partnership between NHS and local authority. Employed district nurses delivering health checks	
Other partners		
Carers Northumberland	Provided carer support workers delivering concentrated work with 6 GP practices. Also took referrals from nurses conducting health checks.	
NHS North of Tyne commissioners	Supported the pilot, ensuring positive links with existing work streams.	
Links with other local organisations third sector and independent sector providers (unofficial partners) including:	Referrals were conducted to and from these organisations (e.g. referrals from nurses conducting health checks to Tynedale Leisure for healthy life schemes). These partners also raised awareness of the project to stimulate referrals.	
Alzheimer's Society; Tynedale Leisure; Tynedale Hospice; Escape; Stars.		

Demonstrator Site: Redbridge Type: Health Checks

Summary of activity

Delivery in this site involved provision of holistic health and well-being checks to carers, generally in their own homes. Each clinical check was conducted first by a qualified nurse, followed by a well-being check which was generally conducted by a well-being worker. Health checks were offered in flexible slots including evenings and Saturdays. A carer action plan was then co-produced with the carer. The site also conducted 12 and 26 week reviews, which evaluated each carer action plan and assessed whether the referrals recommended in the health and well-being check had been made, and agreed actions had been carried out. Health checks were targeted at carers of people at high risk of admission, who were identified using a risk stratification tool (a computer database identifying carers at risk from certain medical conditions).

Objectives of the Redbridge partnership

-600 carers of patients at risk of admission to hospital to receive an holistic health and well-being check (HAWBC), 500 carers to receive reviews at 12 weeks, and 400 to receive reviews at 26 weeks.

-To use a risk stratification tool (health analytics) to identify those carers of patients at risk of emergency admission to secondary care and to prioritise the delivery of checks to those carers looking after people at the highest risk of emergency admission.

-To raise awareness of carer needs and services with GP practices through adopting a carer identification and referral scheme and distributing a carer awareness questionnaire to practices.

-To offer to deliver an holistic HAWBC at a carers' home and at an appointment time convenient to them.

-To provide respite to carers who needed to attend follow up appointments in primary care in order to reduce barriers to accessing primary care.

-To signpost / refer carers to other services and support provided by social care or health providers.

-To complete a cost benefits analysis of a study group of carers receiving HAWBC before 1st October 2010. To compare the number and type of interventions of the secondary care costs of both the carers and the people they look after (the cared for person) received in the six months before and in the six months after the carer receiving the HAWBC.

Methods used to engage carers in the services offered		
Posters / leaflets.	\checkmark	
Advertisements in local media (radio, newspapers).	\checkmark	
Outreach in local communities through providers / partner organisations.		
Television advertisements / promotional DVDs.		
Recruitment through GP practices.	\checkmark	
Events and road shows.		
Mail outs to carers / cared for persons.		
Websites.		
Other.	\checkmark	

Members of partnership		
Lead partner	Role / Description	
NHS Redbridge	Management and oversight of the project. Chaired the steering group.	
Other partners		
London Borough of Redbridge	A strategic partner, involved in setting up the carers' advisory group and on the evaluation sub-group. Worked with the PCT on the bid initially.	
Outer North East London Community Services	Provided nurses to deliver the clinical aspects of the check.	
Redbridge Carers Support Service	Provided well-being workers to deliver the well-being aspect of the check.	
Crossroads	Were not an official partner, but have provided support to the project e.g. promoting the project to GPs.	
Age Concern	Were not an official partner but distributed leaflets / publicity about the project.	
Redbridge Concern	Not an official partner but distributed leaflets / publicity about the project focusing on mental health.	

Target groups mentioned in the site bid

Carers of people with substance misuse problems.

Carers of people with learning disabilities.

Carers of people with a long-term condition.

Workforce carers.

Parent carers.

Young carers.

BME carers.

Bereaved / NEOL carers.

Carers of people at high risk of admission.

	Local evaluation report received by NET	Produced internally / externally
Yes		Internal, part two carried out in conjunction with University of East London

Demonstrator Site: Tower Hamlets Type: Health Checks

Summary of activity

Health checks at this site were delivered by dedicated nurses. The site also had a work-stream for young carers, which included carers' events at the local youth and leisure centre, and working with schools and leisure centres to recruit carers. GP engagement was also a main focus of carer activity.

Objectives of the Tower Hamlets partnership

-Complete 1200 health checks.

-GP engagement with a possibility of sustaining the project with the Health Trainers.

-Create strong networking links with local organisations, such as, THINK, THRIVE, the Drug and Alcohol Action Team, Youth Centres, Family Action Group etc.

-Carry out a local evaluation of the project.

-Hold publicity events.

-To set up carers registers in GP practices.

-Conduct a health checks review (of carers who have had health checks within quarters one and two).

Methods used to engage carers in the services offered	
Posters / leaflets.	
Advertisements in local media (radio, newspapers).	\checkmark
Outreach in local communities through providers / partner organisations.	\checkmark
Television advertisements / promotional DVDs.	
Recruitment through GP practices.	\checkmark
Events and road shows.	\checkmark
Mail outs to carers / cared for persons.	
Websites.	\checkmark
Other.	\checkmark

Local evaluation report received by NET	Produced internally / externally
Yes (draft report received)	External, by 'Arup Healthcare Consulting'

Members of partnership		
Lead partner	Role / Description	
London Borough of Tower Hamlets	Provided the health check team, employed the nurses who conducted the health checks.	
(Adult Health and Well- being)		
Other partners		
NHS Tower Hamlets (PCT)	Had an advisory role around commissioning, GP PLT groups, local day centres and the public health team. Also had a role in sharing information and making referrals.	
Tower Hamlets Carers' Centre	The project manager was based at the Carers' Centre. They also worked with GP practices and partner organisations.	
Alzheimer's Society	Had a representative on the steering group, also on the SINK board. They made referrals to the project.	
Other organisations linking with; MIND, faith groups,	Made referrals to the project and were involved in the recruitment of carers.	
mosques and other BME services.		

Target groups mentioned in the site bid
Carers of people with substance misuse problems.
Carers of people with mental ill-health.
Carers of people with dementia.
Carers of people with learning disabilities.
Carers of people with physical disabilities.
Carers of people with a long-term condition.
Parent carers.
Young carers.
BME carers.
Bereaved / NEOL carers.
Carers of people with sensory disabilities.

Demonstrator Site: Trafford Type: Health Checks

Summary of activity

Support workers provided health and well-being checks to carers in their own homes. This involved completing the detailed 'life-style and well-being questionnaire' with carers, which addressed issues around emotional and general health and included a symptoms checklist, lifestyle assessment and health screenings. Following the health check the carer and support worker would complete an action plan together. After this, a nurse advisor would review the results and compose a summary to pass on to a GP, highlighting any areas for concern. The project also provided health awards to carers; a one-off payment they could spend on an activity of their choice provided it that would impact positively on their health and well-being. The site also delivered carer awareness training to professionals. Other elements of the delivery included stress management training, and health days for carers.

Objectives of the Trafford partnership

-To deliver 400 health checks to carers.

-To educate 100 professionals about carers, their needs and available services.

-Hold six health events to promote healthy activities, health education and coping strategies for carers, with 300 newly identified carers attending.

-Educate and support 140 carers via 1:1 training in stress management, smoking cessation and healthy eating / drinking.

-To have 250 carers participate in new healthy activities through the receipt of health budgets.

-To have 200 carers receive a diagnosis / identification / treatment.

-To have 100 carers feel part of shaping / developing project.

Methods used to engage carers in the services offered		
Posters / leaflets.	\checkmark	
Advertisements in local media (radio, newspapers).	\checkmark	
Outreach in local communities through providers / partner organisations.	\checkmark	
Television advertisements / promotional DVDs.		
Recruitment through GP practices.	\checkmark	
Events and road shows.	\checkmark	
Mail outs to carers / cared for persons.		
Websites.		
Other.	\checkmark	

Members of partnership		
Lead partner	Role / Description	
Trafford PCT	Had an objective monitoring and oversight role with the Senior Responsible Officer based within the organisation. Also had a guiding role in the development of health checks instruments. Ensured engagement by key organisations. Also provided funding and clinical staff and promoted the project.	
Other partners		
Trafford Carers' Centre	Lead on delivery of the project. Health checks were carried out by support workers based at the Carers' Centre. Provided carers health budgets, marketing and promotion and quality assurance. Implemented the project, processed all operational funding for the project and kept financial records.	
Trafford Borough Council (TMBC)	Had a role monitoring / promoting / overseeing the project.	
Trafford Crossroads	Provided respite to carers to enable them to have a health check or attend a clinic or event.	

Target group information
Carers of people with substance misuse problems.
Carers of people with dementia.
Older carers.
BME carers.
Carers in areas of deprivation.
Carers in areas of high health inequalities.
Complex conditions other than those specified.

Local evaluation report received by NET	Produced internally / externally
Yes	Internal

Demonstrator Site: Bolton Type: Better NHS Support for Carers

Summary of activity

There are various different strands to the Bolton site's services:

Training for staff and carers: including carer awareness training, which included the recruitment of carer champions. Carers were given training on mental health and providing support.

Physical health and well-being services: physical health / well-being assessments for carers, and signposting to relevant services.

Direct payments: the local authority conducted Carer's Assessments, and if a breaks need was identified, carers were awarded a £75 payment. With this, efforts were made to increase carer identification and likewise the number of Carer's Assessments undertaken. Each carer who received a direct payment through the DS was given a questionnaire and follow-up form.

Improving carer standards in mental health in-patient wards: this involved working with inpatient services by developing and improving carer standards, confidentiality / involvement with discharge policy. The 'Triangle of Care' document provided a benchmark for which to audit all in-patient areas in Bolton, with efforts made to improve engagement of both carers and staff.

Young-carers service: Barnardo's were contracted to support young carers and make liaison visits to schools, mental health teams, and primary care, among others, to identify young carers.

Befriending service: carers were identified to support other carers, in keeping with the 'expert carer role' discussed in the National Strategy.

Developing a residential hub for people with dementia: this was a late addition to the project and involved the development of a specialist resource for service users and carers of people with a dementia type diagnosis.

Objectives of the Bolton partnership

-To improve the identification of carers of people with mental health problems in all communities in Bolton.

-To ensure comprehensive Carer's Assessments are offered to all carers of people with mental health problems.

-To identify gaps in services to inform further service improvement and commissioning plans.

- To develop flexible, innovative ways of improving the health and well-being of carers across the care pathway.

-To specifically improve involvement and support of carers during the in-patient stay and discharge process of the individual with mental health problems.

-To support carers in accessing a range of services and support available e.g. by developing good information, procuring a befriending scheme from the voluntary sector to support them in enjoying a life of their own alongside their caring role.

-Further develop the range of personalised services and support across the care pathway and across the age range.

-To embed ways of working in partnership with carers for all professionals by reinforcing a change in culture and practice by the development of innovative ways of training e.g. discovery interviews, shadowing of carers by professionals, exploring stages of caring, information sharing and confidentiality, staff induction.

-To explore opportunities to raise awareness of the role of carers in training curriculums within local educational facilities and ensure that local training and development events contribute to raising the profile of carers within service delivery.

-To develop an outcome based evaluation framework for mental health provider services to inform continuous service improvement.

Members of partnership		
Lead partner	Role / Description	
Greater Manchester West Mental Health Trust	Managed and oversaw delivery. Also chaired the steering group.	
Other partners		
Making space	Provided the befriending service.	
Barnardo's	Commissioned by the project to provide support to 30 young carers.	
Bolton PCT	Were on the steering group.	
Bolton Metropolitan Borough Council	Made direct payments and were on the steering group.	
Bolton Acute Hospital NHS Trust	Were on steering group.	

Methods used to engage carers in the services offered		
Posters / leaflets.	\checkmark	
Advertisements in local media (radio, newspapers).	\checkmark	
Outreach in local communities through providers / partner organisations.	\checkmark	
Television advertisements / promotional DVDs.		
Recruitment through GP practices.	\checkmark	
Events and road shows.		
Mail outs to carers / cared for persons.		
Websites.		
Other.		

Target groups mentioned in the site bid	
Carers of people with mental ill health.	
Carers of people with dementia.	
Older carers.	
Young carers.	
BME carers.	

Local evaluation report received by NET	Produced internally / externally
Yes	Internal

Demonstrator Site: Halton and St Helens Type: Better NHS Support for Carers

Summary of activity

This site formed a team of carer support workers within the Acute Trust who were employed in recognising, identifying and supporting carers; training staff to identify carers; and setting up carer pathways. Additionally, a benefits advice service was created where, if carers were in receipt / eligible for benefits, they were referred on for a benefits check, in which an advisor assisted them in applying for benefits. Two GP link workers were based at the two carers' centres, and were involved in delivering carer awareness training to practice staff, raising the profile of carers, and supporting staff to identify carers. At the same time a Carers Charter was developed for the Trust.

Objectives of the Halton and St Helens partnership

-To establish carer pathways which take account of consent, confidentiality and information sharing issues (these may be different within each department / team / ward).

-To involve carers in the planning, development and review of the project.

-The pathway will ensure that:

-Carers are identified

-Carers are respected as equal partners in regards to diagnosis, treatment and discharge.

-Carers are offered practical and emotional support via Carer Support Workers.

-Carers become integrated as part of ward multidisciplinary teams / Multi-Disciplinary Team reviews / discharge plans.

-Carers are linked into ongoing community support.

-That links are made between carers from and / or to primary care services.

-There is greater awareness of carer needs by GPs, clinicians and acute hospital staff.

Methods used to engage carers in the services offered	
Posters / leaflets.	\checkmark
Advertisements in local media (radio, newspapers).	
Outreach in local communities through providers / partner organisations.	
Television advertisements / promotional DVDs.	
Recruitment through GP practices.	\checkmark
Events and road shows.	\checkmark
Mail outs to carers / cared for persons.	
Websites.	
Other.	\checkmark

Members of partnership		
Lead partner	Role / Description	
NHS Halton and St Helens	Managed / oversaw the project. Also were involved in managing the budget, chairing meetings and recruiting staff.	
Other partners		
St Helens and Knowsley Teaching Hospitals NHS Trust	St Helens Hospital and Whiston Hospital are the sites where hospital services were provided as well as carer awareness training. Carer pathways were also established within different wards and departments in these hospitals.	
St Helens PRTC Carers' Centre	ers' Employed and line managed the majority of delivery staff (including GP link worker). Were also on the project board and received carer referrals.	
Halton PRTC Carers' Centre	Employed and managed a GP link worker. Were also on the project board and received carer referrals.	
St Helens Council	Were on project board, also offered support and advice.	
Halton Council	Were on project board, also offered support and advice.	

Target group information

Carers of people with a long-term condition.

Workforce carers.

BME carers.

Bereaved / NEOL carers.

	Local evaluation report received by NET	Produced internally / externally
Yes		Internal

Demonstrator Site: Hastings and Rother Type: Better NHS Support for Carers

Summary of activity

There were several aspects to the service provided by this site, the first a carer liaison service based in both primary and secondary care. In primary care, this involved Carer Liaison Support Workers (CLSW) working with six practices over the lifetime of the project. The CLSW would provide carer awareness training and provide one-to-one support for carers. In secondary care, one Carer Liaison Co-ordinator and two Carer Liaison Workers worked in two acute hospital settings to deliver carer awareness training to staff and to develop a carer referral system and Carer Liaison Service to support carers. The site also raised staff awareness of carer needs via best practice guidelines and a Care Passport scheme. This scheme enabled patients to communicate with staff by encouraging carers to record the patient care needs, preferences and communication requirement. Health checks for carers were also registered at six GP practices.

Objectives of the Hastings and Rother partnership

Carer Liaison Service:

-Design and deliver a service which meets the national aim of 'better NHS support to carers' and the objective of 'delivery of the Carer Liaison Service' across primary care and secondary care settings.

Carer Health and Well-being Checks:

-Improve or maintain the physical and emotional well-being of carers registered at six GP practices across East Sussex.

-Pilot delivery of a Carer Health Check tool within GP practices.

Local Service Evaluation:

-Develop and undertake a local service evaluation of the Carer Liaison Service delivered in both primary care and secondary care settings.

-Measure the local outcomes of the Carer Liaison Service.

Methods used to engage carers in the services offered	
Posters / leaflets.	\checkmark
Advertisements in local media (radio, newspapers).	
Outreach in local communities through providers / partner organisations.	\checkmark
Television advertisements / promotional DVDs.	
Recruitment through GP practices.	\checkmark
Events and road shows.	
Mail outs to carers / cared for persons.	
Websites.	
Other.	

Members of partnership		
Lead partner	Role / Description	
NHS Hastings and Rother	Oversaw the project and chaired the steering group. Had a role encouraging engagement from GPs / wards.	
	GP practice staff undertook training delivered by liaison workers in identifying and referring carers.	
Other partners		
NHS East Sussex Downs and Weald	GP practice staff undertook training delivered by liaison workers in identifying and referring carers.	
East Sussex Hospitals Trust	Were the site for the carer liaison service. Hospital staff participating in training around carer awareness and identifying and referring carers.	
Care for the Carers	Led on the delivery of the project, including the carer liaison service.	
East Sussex County Council (ESCC) - Adult social care and children's services.	Were part of steering group. Carried out and reported on Carer's Assessments.	

Target groups	s mentioned ir	the site bid
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Rurally isolated carers.

Young carers.

Male carers.

BME carers.

Gypsies and Traveller carers.

Carers in areas of deprivation.

Carers in areas of high health inequalities.

Local evaluation report received by NET	Produced internally / externally
Yes (draft report received)	Internal

Demonstrator Site: Northamptonshire Type

Type: Better NHS Support for Carers

Summary of activity

There were various different strands to the provision of services at this site: 1) Carer Assessment and Support workers (CASWs) worked in primary care, employed in 23 GP practices. Their role included supporting each practice to identify carers, assessment and action planning with carers and professional awareness and development; 2) an information strategy aimed at improving information about carers / for carers, which included a campaign website, information pack, carer database and information / advice line, carers' award scheme and training for staff around raising awareness of carers; 3) joint commissioning between the PCT and the local authority offered services to support carers e.g. emergency respite care or sitting services; 4) a young adult transition care worker identified and supported young carers as they transfer from children to adult services; 5) carer-led social enterprise which included an administration centre for carers, four 'carers cafes' where carers could meet and socialise, use the Internet, get training, and access information; 6) Pilot Carers Personal Health Budget Pilot which worked closely with the GP commissioning consortia, the site developed a carer personal health budget pilot alongside a personal health budget pilot led by the consortia as part of a national study; 7) local evaluation by working in partnership with the local university to develop, implement and analyse the evaluation plan utilising GP practice surveys, carer surveys and cost / benefit analysis.

Members of partnership		
Lead partner	Role / Description	
NHS Northamptonshire	Managed and oversaw project. Provided strategic support and led on the bid.	
Other partners		
Northamptonshire Carers	Hosted and managed the Carer Assessment and Support Worker (CASW) team. Participated on the project board and were involved in bid writing. The director was involved in strategic elements of the project, ran the carers information / support telephone line and supported the development of a carers social enterprise.	
Northamptonshire County Council	Were involved in bid writing and participating with joint commissioning with the PCT. Social services also received carer referrals from CASWs.	
Nene Commissioning (GP Consortia)	Provided access to GP leadership and engagement providing a 'way in' for carer support workers to work with GPs. They also participated in the personal health budget.	
Communications Management	An external agency contracted to assist with information strategy and in carrying out publicity / marketing activities.	
Carers Thematic Partnership	An umbrella organisation incorporating various local organisations which offer support to carers. It was involved in the original bid and the development of project. The Demonstrator Site project team attended Carers Thematic Partnership meetings. The Partnership facilitated carer involvement / feedback, connected the project to broader carers issues and created contact with 'hard to reach' partners.	
Carers UK	Conducted external training.	

Methods used to engage carers in the services offered	
Posters / leaflets.	\checkmark
Advertisements in local media (radio, newspapers).	\checkmark
Outreach in local communities through providers / partner organisations.	\checkmark
Television advertisements / promotional DVDs.	
Recruitment through GP practices.	\checkmark
Events and road shows.	
Mail outs to carers / cared for persons.	
Websites.	\checkmark
Other.	

Target groups mentioned in the site bid

Carers of people with mental ill health.

Carers of people with a long-term condition.

Young carers.

BME carers.

Objectives of the Northamptonshire partnership

<u>Joint planning / commissioning:</u> -To create an identified Carers Health Lead within the PCT, working with third sector, GP Commissioning Consortia, local authority, GPs and provider services.

- Institute partnership working with Integrated Care Organisation (ICO).

-To employ Carer Assessment and Support Workers (CASWs) to stimulate engagement and partnership working. -To incorporate carer involvement network into Links.

-To appoint a Joint Carer Commissioner to support development of joint working arrangements to support carers. <u>Professional awareness and development:</u> -CASWs to map, develop and implement the carer pathway.

-To roll out a single assessment process into primary care and deal with pressure points.

-To identify information sharing issues and implement protocols currently being developed.

-To run (with carers) healthcare professionals' carer awareness training and identify issues.

-Audit health / social care information systems for carer related data, e.g. QOF registers.

-Explore ways to record and flag up carers' information and needs.

-Run an information campaign to identify 'hidden' carers and staff who are also carers for target initiatives.

-Work with the County Council to identify and support carers who are at risk of abusing or being abused.

Information strategy: -To develop and implement an information campaign targeting hidden carers and health and social care professionals.

-Co-ordinate dissemination of information to and about carers.

-Develop and implement a County Carers Award scheme.

-Update the carers directory.

-Encourage wider display and provision of carer information.

-Create a carers database, and information and advice line

<u>Healthier carers:</u> To develop a GP practice CASW Team, targeting 23 pilot practices across the county, monitor and evaluate.

-Primary care mental health well-being teams to target carers and accept direct referrals from CASWs.

-Formalise links between the Carers' Project and Pro Active Care Project to provide support and assistance for independent living.

-Develop, implement and evaluate Young Adult Carer Support Service, targeting 18-25 year olds.

-Roll out and evaluate carers' personal health budgets pilot.

-Recruit current / former carers as trained, accredited peer support workers, trainers and / or support planners.

-Provide peer support groups for carers of people with dementia.

-Develop and promote social enterprise opportunities for former carers to deliver practical support, particularly crisis and 'respite' support, including emergency 'respite at home' services.

-To develop and implement carer-led social enterprise to deliver four carer cafes; free holiday accommodation for carers; carer training and development.

Local evaluation: - Develop a mechanism for collating and analysing cost / benefit data.

-Recruit and train a team of carers as evaluators.

Local evaluation report received by NET	Produced internally / externally
Yes (incomplete)	External, by Centre for Health and Well-being Research

Demonstrator Site: South West Essex Type: Better NHS Support for Carers

Summary of activity

This site did not focus on providing direct services for carers; instead it recruited and signposted carers to existing services, provided carer awareness training for NHS staff, and identified and trained carer champions to be employed in health services. Carer recognition workers worked in different areas of the NHS (e.g. GP practices or hospital wards) and were involved in raising carer awareness, developing systems / processes for identifying carers, delivering carer awareness training sessions, and developing referral pathways to carer support. South West Essex also launched the 'Who Cares?' website which provided information for carers and professionals.

Objectives of the SW Essex partnership¹⁰

-Enhance existing procedures to enable GPs to identify, register and refer carers at the earliest opportunity to appropriate services to prevent carer breakdown / hardship.

-Support carers within primary and acute care including promotion of new 'Care Passport' and emergency planning systems for carers.

-Increase numbers of Carer's Assessments.

-Provide carers with three health and well-being assessments to monitor the impact of the project.

-Work with GP practices to provide specific information about conditions to help carers in their role.

-Ensure carers involvement in care pathway by developing guidelines for practices.

-Improve communication between primary and acute care.

Methods used to engage carers in the services offered	
Posters / leaflets.	
Advertisements in local media (radio, newspapers).	\checkmark
Outreach in local communities through providers / partner organisations.	\checkmark
Television advertisements / promotional DVDs.	
Recruitment through GP practices.	\checkmark
Events and road shows.	\checkmark
Mail outs to carers / cared for persons.	
Websites.	√
Other.	\checkmark

¹⁰ Two different sets of objectives were received by the NET team. The objectives here are taken from the South West Essex site bid.

Members of partnership		
Lead partner	Role / Description	
NHS South West Essex	Provided commissioners and distributed materials to 'GPs / pharmacists / opticians'.	
Other partners		
Basildon and Thurrock University Hospitals NHS Trust	Provided carers champions and had a role identifying carers.	
South Essex Partnership University NHS Foundation Trust (SEPT)	Involved in providing access to GP practices and all clinical areas. Recruited carers' champions and arranged staff training to raise staff carer awareness.	
Thurrock Council	Participated in development of shared Carer's Assessment document	
Essex County Council	Involved with 'carers development / social services'	
Carers UK	Involved in developing carer awareness training and the training of carer trainers.	
Anglia Ruskin University	Conducted an independent local evaluation and trained carer volunteers to conduct interviews.	

Target groups mentioned in the site bid	
Carers of people with mental ill health.	
Carers of people with dementia.	
Carers of people with learning disabilities.	
Older carers.	
Young carers.	
BME carers.	

	Local evaluation report received by NET	Produced internally / externally
Yes		External, by Anglia Ruskin University.

Demonstrator Site: Swindon Type: Better NHS Support for Carers

Summary of activity

There were various strands to delivery of services in this site, the main elements included:

Pathway development - three carer pathways were put in place, supported by detailed guidance and referral criteria, and were being piloted and evaluated.

Carer Liaison Team - a team of staff and volunteers were put in place to identify carer needs, facilitate communication, information provision and training.

Training - the site provided modular carer awareness training to professionals, including flexible options such as a carer training DVD, and a distance learning tool. It also trained Carers Leads and colleagues to deliver training themselves to reduce the need for external training.

Information and assessment documentation - carers' information packs were developed and distributed across the health and social care sector. A range of assessment documents were developed and piloted. Information points across the health and social care sector were put in place, including points in 20 surgeries, information hubs in hospitals, and information trolleys which go round hospital wards.

Accreditation - development of a Carers Charter and creation of a practical workbook for use by health and social care teams. Health and social care services were accredited against the Carers Charter.

Communications - various communications initiatives were developed including: awareness raising events; internet pages / sites; employee e-newsletters and updates; a GP bulletin; printed literature (e.g. posters, leaflets) advising on support and help for carers; a carers' forum; a carers' café; ad hoc drop-in sessions / meetings for carers and health and social care professionals; local media (press / radio) articles; a DVD and diversity toolkit for working with BME carers.

Volunteer role development - volunteers in a range of organisations received carer awareness training to expand their roles and build their expertise in working with carers. Volunteer roles included: working in local hospitals and Prospect Hospice; a befriending / carer home visit service; and running the carers café.

'Carer leads' - building on earlier carer lead roles, the project aimed to support the development of roles across the teams in health and social care. sector Three networks of carer leads were developed and supported, including a new network within primary care.

Objectives of the Swindon partnership

-To develop carer pathways focusing on how carers come into contact with NHS.

-Three specific pathways developed for: primary care; acute / hospital based care; community based services.

-To develop clear referral protocols and supporting guidance between primary, acute, community and mental health services.

-With the pathways above guidance would be developed to complement them.

-To audit carer documentation and revise documents developed with carers.

-To carry out a baseline consultation followed by development and piloting of a range of assessment tools.

-To create additional Carer Lead roles across the health and social care sector.

-To develop a Carer Liaison Team to support the project and work on a group and individual basis with carers and professionals.

-To provide a modular training programme for professionals including frontline staff.

-To develop an accreditation system to recognise and celebrate good practice.

-To develop volunteer roles to support statutory services with a focus on out-of-hours support.

Members of partnership		
Lead partner	Role / Description	
Swindon PCT	Performed a project management role, provided a carer liaison team and access to GP practices.	
Other partners		
Swindon Carers	Were part of the steering group and provided support workers to work one to one with carers.	
Prospect Hospice	Were a voluntary sector partner on 'end of life' / palliative care issues. On the steering group and contributed to the development of the project.	
Great Western Hospitals NHS Trust	Were on the steering group. They also piloted training and used the carer pathways.	
Avon and Wiltshire Partnership	Worked with the PCT to develop carer pathways and were involved in focus groups and other events for carers. They were also on the steering group.	
Swindon Borough Council	Had a governance role, functioning as an approval body. They were part of the steering group. Swindon Borough Council's joint community teams were involved in service delivery.	
Bournemouth University	Conducted the local evaluation.	

Methods used to engage carers in the services offered	
Posters / leaflets.	\checkmark
Advertisements in local media (radio, newspapers).	\checkmark
Outreach in local communities through providers / partner organisations.	
Television advertisements / promotional DVDs.	
Recruitment through GP practices.	\checkmark
Events and road shows.	
Mail outs to carers / cared for persons.	
Websites.	\checkmark
Other.	

Target groups mentioned in the site bid	
Carers of people with mental ill health.	
Carers of people with dementia.	
Young carers.	
BME carers.	

	Local evaluation report received by NET	Produced internally / externally
Yes		External, by Bournemouth University

Demonstrator Site: West Kent

Type: Better NHS Support for Carers

Summary of activity

This project involved a 'two-pronged' model, with two main aspects. The first aspect involved 'carers support workers' in primary and secondary care whose role was to raise awareness of carer needs, provide support, information, advice, and advocacy for carers, and signpost them to other organisations / further support. There were six carer support workers, three based in GP practices, and three based in hospitals. Carer Support Workers in GP practices were also involved in encouraging carers to have health checks and Influenza vaccinations, while those based in hospitals aided carers to take a more active role in discharge planning, and supported the implementation of training programmes. The second aspect was an extensive bespoke training programme for NHS / social care staff and carers, tailored to particular target groups. The staff training aimed to improve understanding and responsiveness to carer needs. The carer training was based on Caring With Confidence modules and NHS West Kent materials. Other activities included innovative marketing activities to recruit carers not in contact with voluntary or statutory organisations including: posters and flyers; advertising on social networking sites; and the development of personal organisers for carers' health and social care needs.

Objectives of the West Kent partnership

To enable identification of carers.

To raise carers' awareness of available NHS support services.

To provide information and support to carers.

To build awareness amongst NHS organisations' staff to support carers.

To provide high-quality and tailored support to carers.

Methods used to engage carers in the services offered	
Posters / leaflets.	\checkmark
Advertisements in local media (radio, newspapers).	
Outreach in local communities through providers / partner organisations.	
Television advertisements / promotional DVDs.	
Recruitment through GP practices.	\checkmark
Events and road shows.	
Mail outs to carers / cared for persons.	
Websites.	\checkmark
Other.	

	Members of partnership
Lead partner	Role / Description
NHS West Kent	Held overall responsibility for the Pilot Project and there were three Project Management Staff managed within the PCT. Activities of the PCT staff included: management / supervision, raising awareness with GPs, meeting with partner organisations and monitoring and evaluation.
Other partners	
Kent County Council	Was a part of the steering group. Reviewed Carer's Assessments with the PCT and worked with the PCT to schedule and commission training for social care staff.
Carer First	Managed two carers support workers.
NWK Carers	Managed two carers support workers.
Maidstone Carers	Managed two carers support workers.
Carers UK	Involved in the development of bespoke training materials.

Target groups mentioned in the site bid Carers of people with mental ill-health. Carers of people with learning disabilities. BME carers. Gypsies and Traveller carers. Carers in areas of deprivation.

Local evaluation report received by NET	Produced internally / externally
Yes (incomplete)	Internal

Appendix C Additional Supporting Information

Additional supporting information, referred to in various parts of the report, is presented here.

Table C.1 Care	Table C.1 Carers' Breaks sites: lead partner details and partner types numbers												
Site name	Lead Partner(s)	Other partners											
		Local Authorities	PCTs	Other NHS organisations	Carers' centres / carers' organisations	Other voluntary organisations	Other ²						
Bath and NE Somerset	Bath and NE Somerset Council / NHS Bath and NE Somerset	1	0	0	0	0	5						
Bristol	Bristol City Council	0	0	1	2	2	2						
Derby	Derby City Council	0	1	2	3	5	1						
East Sussex	East Sussex County Council	0	0	1	2	2	# ³						
Hertfordshire	Hertfordshire County Council	0	0	1	2	1	1						
Lewisham	Lewisham Council	1	1	0	1	1	0						
Liverpool	Liverpool City Council	0	1	1	1	1	1						
Nottinghamshire	Nottinghamshire County Council	1	0	0	4	2	1						
Suffolk	Suffolk County Council	1	0	1	3	2	1						
Sunderland	Sunderland City Council	0	1	1	1	0	0						
Torbay	Torbay Care Trust	1	0	1	1	3	2						
Warwickshire	Warwickshire County Council	0	0	2	0	0	1						

Notes: Table shows total number of partners reported during the DS programme. 'Partners' refers to both paid delivery partners and unofficial partners involved in engaging carers or other activities. ¹ Organisations not delivering support or services exclusively or specifically for carers. ² Includes universities delivering local evaluations, private businesses and others. A full list of partners for ever

Demonstrator Site is given in the individual site summaries in Appendix B. ³ Number not specified by site but indicated to be numerous.

Table C.2 Health Check sites: lead partner details and partner types numbers												
Site name	Lead Partner(s)	Other partners										
		Local Authorities	PCTs	Other NHS organisations	Carers' centres / carers' organisations	Other voluntary organisations ¹	Other ²					
Camden	London Borough of Camden	0	0	57	2	100						
Devon	NHS Devon	1	0	35	3	2	# ³					
Northumberland	Northumberland Care Trust	0	0	# ³	1	# ³	# ³					
Redbridge	NHS Redbridge	2	0	0	2	2	0					
Tower Hamlets	LB of Tower Hamlets	0	1	10+	1	2+	# ³					
Trafford	Trafford PCT	1	0	0	2	0	0					

Notes as for Table C3

Table C.3 Better	Table C.3 Better NHS Support sites: lead partner details and partner types numbers											
Site name	Lead Partner(s)	Other partners										
		Local Authorities	PCTs	Other NHS organisations	Carers' centres / carers' organisations	Other voluntary organisations ¹	Other ²					
Bolton	Greater Manchester West Mental Health Trust	1	1	1	0	2	0					
Halton and St Helens	NHS Halton and St Helens	2	0	1	2	0	0					
Hastings and Rother	NHS Hastings and Rother	1	0	# ³	1	0	0					
Northamptonshire	NHS Northamptonshire	1	0	1	3	0	1					
SW Essex	NHS South West Essex	2	0	# ³	1	0	1					
Swindon	Swindon PCT	1	0	3	1	0	1					
West Kent	NHS West Kent	1	0	0	4	0	0					

Notes: Table shows total number of partners reported during the DS programme. 'Partners' refers to both paid delivery partners and unofficial partners involved in engaging carers or other activities. ¹ Organisations not delivering support or services exclusively or specifically for carers. ² Includes universities delivering local evaluations, private businesses and others. A full list of partners for ever Demonstrator Site is given in the individual site summaries in Appendix B. ³ Number not specified by site but indicated to be numerous.

Table C.4 Methods used in local evaluation studies in the Demonstrator Sites										
Site	How completed ¹	Survey of carers	Interviews / focus groups with carers	Carer feedback forms	Carer case studies	Survey of staff	Interviews / focus groups with staff			
Carers Breaks sites										
Bath and NE Somerset		√	~	√						
Bristol	E		✓				✓			
Derby	E	✓	✓		✓					
East Sussex	E		✓				✓			
Hertfordshire				✓	√					
Lewisham	E	✓	✓							
Liverpool ²	I	√	✓	✓	√					
Nottinghamshire	E	√			√					
Suffolk	I	√			✓					
Sunderland	I		✓	✓			✓			
Torbay ²	В	√	✓	✓	✓					
Warwickshire	I	√		✓	✓	√	✓			
Health Checks sites										
Camden	E	\checkmark	\checkmark		\checkmark	\checkmark	\checkmark			
Devon	В	✓	✓		~					
Northumberland			✓			\checkmark				
Redbridge		√	 ✓ 		✓		✓			
Trafford	E	\checkmark	✓ ✓		\checkmark	√				
Tower Hamlets ²			✓				✓			
NHS Support sites Bolton	1	✓			~	√				
Halton and St. Helens		✓ ✓			◆ ✓	✓ ✓				
Hastings and Rother		• •	✓		• ✓	▼ ✓	✓			
Northamptonshire ²	E	· ✓	· •		-	· √	· ✓			
South West Essex	E	√	√ 			√	√ 			
Swindon	B	√	✓		√	√	✓			
West Kent	B	✓	✓		\checkmark		✓			
Sources: Quarterly Calls, Loca		Poporte	•	•						

Sources: Quarterly Calls, Local Evaluation Reports

Notes: ¹ Local evaluation completed internally (I); commissioned externally using independent evaluator (E) or both (B). ² Some sites submitted evaluation reports which they indicated were 'draft' or 'incomplete' reports.

Table C.5 Plai	Table C.5 Planned versus actual carer involvement in Breaks Sites																					
Site	Planned involvement:												Actual involvement:									
	Project board / task group	Reference group / forum / panel	Design of delivery / evaluation materials	Carer evaluators	Consultation events	Focus groups	Other formative feedback	Delivering training	Developing / allocating Breaks	Training for carer volunteers	Other	Project board / task group	Reference group / forum	Design of delivery / evaluation materials	Carer evaluators	Consultation events	Focus groups	Other Formative feedback	Delivering training	Developing / allocating breaks	Training for carer evaluators	Other
Bath and NE Somerset		~				~	~						~					~				
Bristol	✓	✓										\checkmark	✓									
Derby	✓												✓									
East Sussex												✓								✓		✓
Hertfordshire		✓											✓									✓
Lewisham	✓				✓	✓							✓									
Liverpool								✓				✓		✓				✓				
Nottinghamshire	✓	✓				✓							✓									
Suffolk										✓			✓	\checkmark	✓			\checkmark		\checkmark		
Sunderland	✓	\checkmark					✓		✓			\checkmark		✓						\checkmark		
Torbay	~			~				~			~	~	~	~	~				~			~
Warwickshire							~				✓	~	✓	✓				✓				

Table C.6 Planne	Fable C.6 Planned versus actual carer involvement in Health Check Sites																					
Site	te Planned involvement:											Actual involvement:										
	Project board / task group	Reference group / forum / panel	Carer evaluators	Consultation events	Focus groups	Other formative feedback	Delivering training	Training for carer volunteers	Design of health checks	Design of other materials	Other	Project board / group / task	Reference group / forum	Carer evaluators	Consultation events	Focus groups	Other Formative feedback	Delivering training	Training for carer volunteers	Design of health checks	Design of other materials / initiatives	Other
Camden		✓						\checkmark			✓		✓	✓			✓		✓	✓	✓	✓
Devon		✓										✓	✓							✓	✓	
Northumberland			✓						~		~	✓		~					✓	✓	✓	
Redbridge		✓	✓									✓	✓				✓				 ✓ 	✓
Tower Hamlets											✓	✓										✓
Trafford											✓	✓	✓	✓			✓	✓		✓	✓	\checkmark

Table C.7 Planned	Table C.7 Planned versus actual carer involvement in NHS Support Sites																			
Site	Planned involvement:											Actual involvement:								
	Project board / task group	Reference group / forum / panel	Design of delivery / evaluation materials	Carer evaluators	Consultation events	Focus groups	Other formative feedback	Delivering training	Training for carer volunteers	Other	Project board / group / task	Reference group / forum	Design of delivery / evaluation materials	Carer evaluators	Consultation events	Focus groups	Other Formative feedback	Delivering training	Training for carer volunteers	Other
Bolton		✓				✓		\checkmark		✓								✓		✓
Halton and St Helens		~									~			~			~	~		
Hastings and Rother	~	~				~				~	~						~			
Northamptonshire		✓								✓	✓	✓	✓	✓				✓		✓
South West Essex	✓			✓			✓	\checkmark		✓		✓	✓	✓				✓		✓
Swindon		~			\checkmark			\checkmark				✓								
West Kent											✓									

Table C.8 Cost Savings calculations based on carer coordinator assessments: East Sussex											
Activity	Unit Cost (£'s)	Total No of Instances	Total Savings (£'s)	ESCC Instances	ESCC Savings (£'s)	Health Instances	Health Savings (£'s)	Service User Instances			
MHA Sections Avoided	598 per section	6 sections	3,591	6	874	6	2,716	0			
Weeks in Residential Care under MHA Section Avoided	553 per week	102 weeks	56,455	102	56,455	0	0	0			
Weeks in Nursing Care under MHA											
Section Avoided	562 per week	12 Weeks	6,743	12	6,743	0	0	0			
Hospital Admissions Avoided	2,000 per week										
	for 90 days on										
	average	13 Stays	334,286	0	0	13	334,286	0			
Did Not Attends (DNAs) Avoided	98 per DNA	207 DNAs	20,286	0	0	207	20,286	0			
Weeks in EMI Residential Care Avoided	441 per week	1,145 weeks	413,461	938	413,461	0	0	207			
Weeks in Nursing Care Avoided	535 per week	39 weeks	6,421	12	5,117	12	1,304	27			
Weeks in Residential Care Avoided	376 per week	139 weeks	52,279	139	52,279	0	0	0			
Service User Contributions Saved	110 per week	1,187 weeks	(130,926)	1,187	(130,926)	0	0	1,187			
Total Savings			762,596		404,003		358,592				
% of Total					53%		47%				

Source: East Sussex site document 'East Sussex Carers Demonstrator Strategy Site Savings'.

Notes: The total funding from the DH for 18 months of the project is £610,071; service user contributions are assumed at the minimum level of £110.30 per week; Costs of residential care have been taken at preferred provider rates; Potential savings to service users are estimated at £237k, based on the number of weeks of residential care saved; Savings do not include estimates for staff time and travel, which hasn't been quantified.

Appendix D Sharing Knowledge through the Carers' Demonstrator Sites website

Introduction

Shortly after the start of the national evaluation study, the Department of Health asked the study team to procure, establish and maintain a website to aid communication with and between the 25 Demonstrator Sites (DS). This central web resource was intended to facilitate communication between DS personnel, encouraging them to share information, insights and learning, and to provide them with the information and tools they needed to participate in the evaluation. The website was also designed to provide DS staff with the opportunity to share project documentation, which would contribute to the mapping of new provision.

Website use and engagement

The website went 'live' on 4th December 2009, and throughout the period December 2009 to March 2011 a total of 110 DS staff were provided with a username and a password to access the website. Eighty one members of staff logged in at least once (79% of staff in Carers' Breaks, 73% of staff in Health Checks, and 77% of staff in NHS Support sites with login access).

Site staff's use of the website varied considerably during the course of the DS programme. The number of visits to the website rose steadily and peaked in July 2010 with a total of 86 visits per week, driven by the number of site visits from users at Breaks sites (Figure 1). A decrease was observed from August 2010 onwards.



On average, 14 visits per week were made by Breaks site staff (from 12 Breaks sites), three visits per week were made by Health Checks site staff (six sites), and seven visits per week made by NHS Support site staff (seven sites). During the course of the DS programme an average of 96 visits to the website were made per month by site personnel. A 'core' of consistent users accessed the website on a regular basis, namely the sites in Derby, Nottinghamshire, Bristol, Swindon and Hastings and Rother.

Web pages attracting the highest viewing figures were those homepages of the Bristol, Derby and Hertfordshire sites. Following these, the most viewed pages were:

- Forum pages specifically Breaks sites forums (see 'strategies to encourage website use).
- Individual Carer Record page.
- Research Instruments page.
- Project Directory (providing site contact details).
- Final Contact Event pages (summarising a 'Contact Event' (conference) held by the national evaluation team for DS to share learning from their experiences of their own Demonstrator Site).

Interest in the website continued (at a lower level) beyond the end of DS delivery period of DS (i.e. after March 31st 2011), with 15 visits a month continuing to be made by a variety of Breaks, Health Checks and NHS Support sites in spring and summer 2011.

Sites provided a diverse range of project documentation and supplementary material to share with other sites (Table D1). These documents were also used by the national evaluation team to monitor site activity and for the purpose of documentary analysis.

A small minority of sites uploaded material to the website themselves, but the majority of sites preferred to provide the evaluation team with documents by email for uploading by the Project / Web Administrator. The number of documents provided by each site therefore does not necessarily reflect the site's level of engagement with the website.

Strategies to encourage website use

A variety of strategies were employed to encourage DS personnel to visit the website regularly. A 'website digest', sent to sites every week via email, informed all DS contacts of any new website content uploaded by the evaluation team and DS sites. This received positive feedback in the final quarterly calls with sites.

Three Website Navigation Guides were prepared and made available on the website. A presentation was made by the Web Administrator at a Breaks site contact event and five Break site forums were developed to encourage inter-site communication and discussion. Site forums and social networking facilities were seldom used, however, despite site forums attracting high viewing figures.

Feedback

Feedback on the website was obtained from two sources, the first contact event and the final quarterly call.

Table D.1 Documents submitted to the website by Demonstrator Sites									
Site	Amount	Examples of documents submitted							
Bath and NE Somerset County Council	8	Marketing materials.							
Bristol City Council	9	Marketing, reports, carer feedback.							
Derby City Council	18	Information packs, marketing.							
East Sussex County Council	17	Presentations, evaluation summary and reports, feedback.							
Hertfordshire County Council	101	Budgetary information, implementations plans, carer feedback.							
Lewisham Council	9	Research, reports, questionnaires.							
Liverpool City Council	6	Marketing, local evaluation procedural information.							
Nottinghamshire City Council	5	Case studies, papers.							
Suffolk County Council	53	Marketing, case studies, presentations.							
Sunderland City Council	13	Local evaluation plans, marketing.							
Torbay Care Trust	9	Assessment tools, strategy documents.							
Warwickshire County Council	25	Presentations, strategy documents, agendas of meetings.							
London Borough of Camden	44	Job descriptions, case study documents.							
Devon PCT	32	Marketing, presentations and events, local evaluation.							
Northumberland Care Trust	1	Staff baseline survey.							
NHS Redbridge	15	Project plans and protocol, case studies.							
London Borough of Tower Hamlets	1	Early learning.							
Trafford PCT	21	Minutes, project plans, health check tools.							
Bolton PCT	22	Marketing, surveys, questionnaires.							
NHS Halton and St Helens	31	Presentations, minutes of meetings, reports.							
Hastings and Rother PCT	36	Training packs, reports, status updates.							
Northamptonshire Teaching PCT	4	Project plan, Return in Investment model.							
NHS South West Essex	4	Interim report, resource packs.							
Swindon PCT	61	Assessment tools, carers information packs.							
NHS West Kent	59	Equality monitoring forms, marketing, project plans.							

The website session at the first contact event, held in February 2010, proved the most popular session amongst DS staff, as well as being considered one of the most positive aspects of the event. When asked if they would do anything differently as a result of attending the contact event, the majority of DS staff stated that they would 'try to use the website to contact other project contacts'.

The final quarterly calls, conducted during spring / summer 2011, drew a predominantly positive response from DS staff. The majority of feedback from Breaks site staff was positive, and most felt that it was a useful resource they enjoyed using. However, a number of Breaks site staff also felt that they did not have enough time to visit the website. Two members of staff suggested that the degree to which the website would be used during the project term would be directly proportional to DS staff's familiarity with social networking sites. It was also suggested that 'generational differences shape web use', meaning younger staff were perhaps more likely to engage with the website.

In contrast, the majority of Health Checks sites staff reported that they found navigating the site challenging, and that their ability to view and download documents was impaired by a lack of clarity over how to do so. One member of staff expressed the opinion that the website was complicated. Quarterly calls with NHS Support site staff produced conflicting views on use of the website. A majority of staff considered the website to be useful and informative. However, other considered the website 'difficult', 'complicated' and 'useless'. Lack of time to make use of the website was a recurrent theme.

Technical issues, accessibility and compatibility

In order to construct the website, the national evaluation team considered a number of different content management and web publishing platforms, whilst remaining aware of the key decisive factors of budget, 'lead' time and the website's functional requirements. Approximately £2,000 of the programme's budget was allocated to the development of the website. Additionally, the Department of Health requested that the website should be secure, 'live' within five weeks, and hosted by the University of Leeds.

For the purpose of the evaluation, the Faculty Web Developer considered Wordpress MU (Multi User), an open source blog publishing application, to be the only suitable and economical web authoring tool. Buddypress, an open source social networking package, was used alongside Wordpress as a 'plug-in' (a means of adjoining specific capabilities to a larger software application), providing the social networking facilities required by the Department of Health.

The Faculty Marketing and Web Team were able to support the Project / Web Administrator to develop the website to deadline, and for minimal cost. However, particular restrictions accompany the convenience of employing an open source content management system. Only a limited number of templates – and therefore style and navigation options – are available. Furthermore a website constructed using Wordpress would have to be customised to incorporate the functional requirements of the Carers' Demonstrator Sites website. The evaluation required social networking to take place online in a closed environment. Wordpress and Buddypress are both tools which seek to encourage wider participation, and a way had to be found to restrict access. Additional plug-ins were written to simultaneously integrate and restrict blog access to particular members of the national evaluation team and site staff, and to provide a customised front page for the site, amongst other specifications.

Ultimately the use of Wordpress required regular modification to fulfil the requirements of both the evaluation and the DS staff.

DS staff accessed the website from their workplace, most often a local authority or a Primary Care Trust, and were obligated to use the browser available on their work PC. An analysis of web traffic statistics demonstrates that 43% of visits to the website were made using Internet Explorer 6. This browser is used by only 10% of the browser user population worldwide. As a result of its declining use and recent security problems, most software upgrades do not support IE6, including a range of Microsoft's own applications, Google applications and YouTube. This means that an IE6 browser user will perceive a number of websites to be faulty and unstable.

Wordpress ceased to provide support for IE6 during 2010; therefore any upgrades subsequent to the website's inception would result in the problems (summarised above) for IE6 browser users. A system update during the early stages of the project did indeed result in problems for users. These problems were resolved, though it became impractical to install upgrades to the system throughout the rest of the project term.

Public sector organisations use custom made inter-organisational applications (to support purchasing for example) written to be used with IE6. Accessing these applications using a web browser other than IE6 would render these applications faulty and problematic. As a consequence, organisations are deterred from upgrading their network browsers as this would present problems and ultimately result in a substantial outlay modifying applications. Furthermore, installation of more up to date computer software, such as Microsoft Office, is often postponed. Consequently a variety of DS staff using a version of MS Office prior to 2007 (the version used by UoL) experienced difficulty reading documents uploaded to the website. PDF files were also unable to be accessed by some website users for a similar reason.

Summary

The above evidence suggests that DS personnel used the website as originally intended: to share learning and information with the evaluation team and other sites; to learn about the evaluation process; and to gain access to the tools to enable them to participate. DS staff visited other sites' profiles, browsing information concerning project objectives, implementation, and any documentation or publicity that had been provided to be shared with other sites. However, facilities created to promote communication and discussion between sites, such as forums and social networking tools, were seldom used.

The only method available to develop the website placed restrictions upon style and navigation. Additionally, compatibility and accessibility were issues for various sites using antiquated computer hardware and software.

With the exception of inter-site communication, the 'Carers' Demonstrator Sites' website fulfilled its purpose, attracted positive feedback from the majority of sites, and retained interest beyond closure of DS.