

Any breakthrough for carers?

The Princess Royal Trust for Carers and Crossroads Care

“The kind of break I need is – anything!”
Brian, a carer



The Princess Royal Trust
for Carers

**CROSS
ROADS
CARE**

a positive partnership between The Princess Royal Trust for Carers and
Crossroads Care

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Executive summary

HM Government refreshed the Carers' Strategy in November 2010 allocating an additional £400m over four years (2011–15) to the NHS for primary care trusts (PCTs) in England to provide breaks for young and adult carers.¹ The Government requested PCTs to work with local authorities and carers' organisations to develop policies, plans and budgets to support carers and make them available to local people.²

The Princess Royal Trust for Carers (The Trust) and Crossroads Care have surveyed 112 PCTs and carers' organisations to measure PCT progress regarding development of policies, plans and budgets, finding that:

- Only 9% have published updated plans to support carers
- 37% of PCTs advised they would not be publishing or updating plans created before the additional allocations and Government guidance
- 54% of PCTs advised that they intend to publish new or updated plans in 2011/12, with dates of publication ranging from July 2011 to March 2012
- 82% of PCTs claimed they had worked with carers' organisations to formulate plans and budgets. However, 40% of PCTs in areas surveyed were judged by local carers' organisations to have not engaged with them at all.

There are breakthroughs in some localities where PCTs, working with local carers' organisations and local authorities have grasped the opportunity to improve support for carers. We are still a long way from being able to say that the NHS has made a breakthrough in reaching an adequate level of support for carers.

We call on PCTs and Government to drive progress to:

- Ensure the additional allocation of funding reaches carers
- Ensure that updated plans and budgets for supporting carers are published by October 2011.
- Ensure future plans, such as Joint Strategic Needs Assessments, highlight support and breaks for carers as a priority.
- Have every lever available to the Department of Health used to ensure that PCTs meet their responsibilities to support carers.

¹ HM Government (2010), 'Recognised, Valued and Supported: Next Steps for the Carers' Strategy'. London: Centre of Information.

² Department of Health (2010), 'The Operating Framework for the NHS in England 2011/12'. London: Centre of Information.

Introduction

The Coalition Government has prioritised improving support for carers³, refreshing the Carers Strategy in England and intending that key elements of the Strategy will be delivered via NHS PCTs. This report measures progress towards this end, and in particular, whether PCTs are working with carers' organisations to create policies, plans and budgets as stipulated by Government.⁴

The Government refreshed the Carers' Strategy in November 2010 publishing 'Recognised, valued and supported: Next steps for the Carers Strategy'. The Government identified four priorities⁵:

1. Supporting those with caring responsibilities to identify themselves as carers at an early stage. Recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages.
2. Enabling those with caring responsibilities to fulfil their educational and employment potential.
3. Personalised support both for carers and those they support, enabling them to have a family and community life.
4. Supporting carers to remain mentally and physically well.

The achievement of these priorities is to be facilitated, at least in part, by a firm commitment to providing the NHS with extra funds to support carers:

"Government – local and national – should reciprocate the support carers show with measures that ease the responsibility of caring. The additional £400 million via the NHS over the next four years to provide carers, including young carers, with breaks from their caring responsibilities is recognition of the vital role they play."⁶

The Trust and Crossroads Care welcomed the Strategy and this commitment. However, £150m previously allocated to the NHS between April 2009 and March 2011 to increase support for carers was found to be

³ HM Government (2010), 'The Coalition: Our Programme for Government'.

⁴ Department of Health (2010), 'The Operating Framework for the NHS in England 2011/12'. London: Centre of Information.

⁵ HM Government (2010), 'Recognised, Valued and Supported: Next Steps for the Carers' Strategy'. London: Centre of Information.

⁶ HM Government (2010), 'Recognised, Valued and Supported: Next Steps for the Carers' Strategy'. London: Centre of Information.

have been predominantly spent on other areas. Our research found that approximately only 25% was used to increase support for carers⁷.

Acknowledging our concerns, the Coalition Government implemented three of the four recommendations that we made to encourage PCTs to use the monies allocated to improve support for carers for that purpose⁸:

1. PCTs must formulate plans and budgets with local authorities and local carers' organisations.
2. These plans and budgets must be made available to local people.
3. The NHS Outcomes Framework 2011/12 has carers as an improvement area and the self-reported quality of life of carers will be monitored in each PCT area.

The NHS Operating Framework states that "PCTs should pool budgets with local authorities to provide carers' breaks, as far as possible, via direct payments or personal health budgets. For 2011–12, PCTs should agree policies, plans and budgets to support carers with local authorities and local carers' organisations, and make them available to local people."⁹

The only recommendation not adopted was that the amount each PCT would receive as a share of the £400m national allocation should be published. The Government has not specified how the £400m will be split over four years (April 2011–March 2015) and as previously, the funds are not ring-fenced, and therefore PCTs are able use the money on other areas.

This is the first of two connected reports. In this report, we scrutinise whether and how PCTs have worked, or are working, with carers' organisations to create policies, plans and budgets and whether these have been or will be made available to local people as Government has requested.

⁷ Conochie, G. (2010), 'Tough Breaks for Carers'. London: The Princess Royal Trust for Carers.

⁸ Department of Health (2010), 'The Operating Framework for the NHS in England 2011/12'. London: Centre of Information.

Department of Health (2010), 'The NHS Outcomes Framework 2011/12'. London: Centre of Information.

⁹ Department of Health (2010), 'The Operating Framework for the NHS in England 2011/12'. London: Centre of Information.

Department of Health (2010), 'The NHS Outcomes Framework 2011/12'. London: Centre of Information.

A second report to be published later in 2011 will analyse whether the additional money made available by national Government has been used by PCTs to increase support for carers.

Methodology

In January 2011, The Trust and Crossroads Care wrote to all PCTs advising them how the NHS Operating Framework affected their responsibilities towards carers and that it guided them to work with local carers' organisations to create plans and budgets regarding carers' services.

We advised them of the contact details for The Princess Royal Trust Carers' Centres and Crossroads Care schemes in their area. If there was neither a Carers' Centre nor a Crossroads Care scheme in that PCT area, we gave them details of a regional manager who could advise them of other carers' organisations in their area.

On 21 April 2011, we sent a letter with a series of questions to 134 PCTs¹⁰ asking whether they were working with local authorities, carers' organisations and carers to create policies, plans and budgets for carers' services. We also asked if and when these would be published. The NHS Operating Framework does not mention working with carers but given the Government's desire for public involvement in healthcare¹¹, we felt this was a valid area to explore.

The questions were asked under the Freedom of Information Act (2000) meaning PCTs should respond within 20 working days. The questions can be found in Appendix 1.

Throughout June, we reissued requests by emailing Freedom of Information Officers at PCTs, some of whom advised there was no record of receiving the original letter, causing a delay in responses. 112 responses were received.

Given PCTs were asked to work with local carers' organisations, we asked Carers' Centres and Crossroads Care schemes for their views on how PCTs were engaging with them to create plans and budgets. These two networks are by far the largest providers of carers' support services in England and cover the greatest geographical scope.

¹⁰ Some local carers' organisations preferred us not to send a Freedom of Information request to their local PCT. We respected these requests.

¹¹ Department of Health (2010), 'Liberating the NHS: Legislative Framework and Next Steps'. London: The Stationery Office

We also contacted other organisations named by PCTs as organisations they have engaged with. Responses from carers' organisations covered 81 PCTs. The survey completed by carers' organisations is in Appendix 2.

The importance of breaks

Breaks for carer are not a luxury, but are vital for the health and wellbeing of carers, who often have little if any support. Without breaks, many carers are not able to continue in their caring role as their health may deteriorate under constant strain. The result can be that some carers require care or hospitalisation themselves:

- A four year study of 392 carers and 427 non-carers aged 66–92 found that carers who were reporting feelings of strain had a 63% higher likelihood of death in that period than non-carers or carers not reporting strain.¹²
- Carers providing high levels of care were associated with a 23% higher risk of stroke;¹³
- 36% of carers who had not taken a break of more than a few hours since beginning their caring role, which is many, experienced mental ill-health compared to 17% of carers who had been able to take such a break.¹⁴

The impact of poor support for carers is reflected in the causes of admission to hospital and residential care. One study found that problems associated with the carer contributed to readmission of patients in 62% of cases and the carers of people readmitted were more likely than other carers to be experiencing ill-health, fatigue and interrupted sleep.¹⁵ Another study of people aged over 75 years old, found that 20% of those needing care were admitted to hospital because of the breakdown of a single carer on whom the person was mainly dependent.¹⁶

¹² Schulz, R & Beach, S, 'Caregiving as a risk factor for mortality'. *Journal of American Medical Association*, Dec 1999, vol. 282 (23), 2215–2219.

¹³ Haley, W et al (2010), 'Caregiving strain and estimated risk for stroke and coronary heart disease among spouse caregivers'. *Stroke*, 41:331-336.

¹⁴ Singleton, N et al (2002), 'Mental Health of Carers'. London: Office for National Statistics, The Stationery Office.

¹⁵ Williams, E, Fitton, F (1991), 'Survey of carers of elderly patients discharged from hospital'. *British Journal of General Practice*, 41, 105-108.

¹⁶ Castleton, B (1998), *Developing a whole system approach to the analysis and improvement of health and social care for older people and their carers: A pilot study in West Byfleet, Surrey*. Unpublished. Referenced by Banks, P (1998) 'Carers: making the connections'. *Managing Community Care*, vol 6, issue 6.

Regarding residential care, carer-related reasons for admission to nursing or residential care are common, with carer stress the reason for admission in 38% of cases.¹⁷ A randomised controlled trial that looked at a Dutch programme of respite provision, coupled with carer support and advice, found that the programme achieved significant delays in transfer to residential care.¹⁸

Carers themselves have consistently stressed the importance to their own lives of receiving support and having a break. Through our 'Give Carers a Break' campaign, carers have been telling The Trust and Crossroads Care why breaks are important to them:

John: "I need a break to get things done at home ... like decorating my mother's bedroom ... it would give me a chance to relax and charge my batteries."

Sarah: "To recharge my batteries and feel emotionally and physically in a good frame of mind."

Louise sums up what the majority of responses have echoed with simply wanting "a few days without stress".

Names changed. See Appendix 3 for more quotes from carers

The striking thing is that carers are not asking for foreign holidays or expensive trips away; they are asking for some small amounts of time to enable them to carry on with some of the everyday tasks they don't have enough time to do.

Respite for carers is often the difference between being able to carry on with caring responsibilities and not being able to carry on. The Trust provides grants to carers in need of respite but the overwhelming demand means that not all of the requests for help can be met.

Colin's story

Colin was awaiting surgery for blocked arteries and his combined stress meant that he was close to breaking point. He hadn't had any form of break for nearly six years and little income due to his significant caring

¹⁷ Bebbington, A, Darton, A, Netten, A (2001), 'Care Homes for Older People: Volume 2. Admissions, Needs and Outcomes'. University of Kent, Personal Social Services Research Unit.

¹⁸ Dröes, R et al (2006), 'Effect of the meeting centres support program on informal carers of people with dementia: results from a multi-centre study'. *Aging & Mental Health*, 10(2), 112-124.

role. The Trust was able to cover travel and hotel costs for a short seaside break giving him a chance to recharge his batteries.

Emily's story

Emily cares for her husband who has MS and is deteriorating significantly. Emily provides all day-to-day care for her husband and was getting very depressed seeing her partner deteriorate and she was reaching the point of exhaustion. Emily has not had a holiday for over six years and The Trust was able to give her a short break with friends.

These examples and the demand for breaks from The Trust's grant programmes are themselves an indication of the lack of support available to carers. Council figures advised that only 47,850 carers across England received their own Direct Payment in 2009/10¹⁹. This low level of carers getting support corresponds with a survey of carers²⁰ which found that only 4% had been assessed and of those 4%:

- 4% reported getting a break in their own home
- 8% reported getting a break away from home
- 16% got a direct payment or personal budget

¹⁹ Niblett, P. (2011), 'Personal Social Services Expenditure and Unit Costs England, 2009-10'. London: The Health and Social Care Information Centre.

²⁰ Niblett, P. (2010), 'Survey of Carers in Households 2009/10'. London: The Health and Social Care Information Centre.

Results²¹

Have PCTs published policies, plans and budgets for carers' services?

25% of PCTs (28 of 112) responding advised that they had published plans and budgets for 2011/12 to support carers. However, these plans were all produced before the Government's announcement of the additional funding and NHS Operating Framework publication, often in 2008 or 2009 covering a four year period.

Whole new strategies need not be produced where there were existing plans covering 2011/12, but they should have been reviewed to take into account the Government's refreshed Carers' Strategy, the extra monies being made available to PCTs and guidance in the NHS Operating Framework. There is no evidence that this has happened in these cases.

A further 12% of PCTs do not refer to previously published strategies and advised that they will not be producing policies, plans or budgets for carers in 2011/12.

Taking those PCTs who have not updated plans and those who have said they will not be publishing plans, 37% of PCTs have not made any progress in developing their support for carers, despite it being seven months since the Government's publication of the Carers' Strategy and NHS Operating Framework 2011/12.

54% of PCTs advised that they are making progress and intend to publish new or updated strategies in 2011/12 with due publication dates ranging from July 2011 to March 2012. One PCT advises that it will publish its plans and budgets in 2012/13. There will be disappointment among carers that PCTs have not responded more quickly to consider the Government's guidance.

This leaves only 9% of PCTs who have published plans (not all published budgets along with plans or even a total allocated to carers' services) revised for 2011/12 taking into account the Government announcements and guidance. PCTs, like NHS Worcestershire that have announced an additional £500,000 investment in carers' services this year, should be applauded for their rapid progress and others should look to see the benefits they gain.

²¹ See Appendix 4 for summary of responses for each PCT

Sunderland invests £630,000 to support carers

Sunderland PCT and Sunderland Carers have worked together to give carers a break they deserve by investing £630,000 for extra services to support them.

Penny Davison of Sunderland PCT explained that supporting carers was key to the care of people with disabilities and long-term illness. "We value and recognise the huge contribution carers make to caring for friends or relatives who may be disabled or seriously ill. We have seen the benefits that providing short breaks to carers can have on their health and wellbeing and are keen to ensure that carers can access a range of quality services that will support them in their caring role."

Ailsa Martin, Chief Executive of Sunderland Carers Centre, said this this will help more carers get a break that they may desperately need: "This extra investment enables us to develop and share very innovative services, including group breaks for isolated carers who maybe didn't take breaks previously because they had no one to go with."

Are PCTs working with carers' organisations?

82% of PCTs surveyed (92 of 112) responded that they had worked with carers' organisations to develop policies, plans and budgets with three more advising they would do so later in 2011/12. 77% of PCTs advised they have worked with carers to do so and another two PCTs advised they would later in 2011/12.

There is a worrying contrast between these responses from PCTs and the responses obtained from local carers' organisations. Between them, carers' organisations participating in our survey work in the areas of 81 of the total 152 PCTs.

30% of PCTs (24 of 81) were judged by carers' organisations to be achieving a good level of co-production with carers' organisations to produce policies, plans and budgets. This meant that local carers' organisations believed that there were continued discussions with good opportunity for input and influence by carers' organisations.

21% were judged by carers' organisations to be achieving a reasonable level of co-production meaning there were some discussions and some consideration of input by carers' organisations. A further 10% of PCTs were judged to be poor at co-production meaning there was little opportunity for input or influence.

Some carers' organisations judged the level of co-production to be good or reasonable even if their input into plans had been minimal but the result was some investment in carers' services by the PCT. Expectations of engagement generally appears to be low.

Many carers' organisations that felt there was no engagement at all by their PCT. 40% of PCTs were judged not to have engaged with carers' organisations at all to develop policies, plans and budgets²². There are a number of instances where a PCT has listed a carers' organisation as being involved and the carers' organisation has described very little involvement or none at all. For example, one carers' organisation, when told that their PCT claims to have worked directly with them remarked "I like the way they think talking to us pre 2009 makes it okay."

Other carers' organisations give examples of where there have been promising engagement with PCTs, but due to personal and structural changes within the PCT these have come to nothing: "We have made several false starts with demonstrable goodwill but the lead commissioner has continually changed (all on temp contracts) for the last 2–3 years". Another explained they have enjoyed good relationships but that "it has all plummeted downhill into a worrying void."

The most depressing response from a carers' organisation was "we might as well not exist."

Close personal relationships and the support of senior staff within the PCT appear to be key for successful co-production. For example, the Carers' Centre in Northamptonshire commented that they had "Excellent support and involvement from the carers' development manager within the PCT and sign up from chief executive and director level". There are also areas where carers' organisations and carers are treated as equal partners, with clear channels to influence decision making.

Richmond Carers Strategy Group commits £281,000 for carers' breaks

The PCT, local authority and carers' organisations such as Richmond Carers' Centre and Crossroads Care Richmond, have worked together to produce plans to provide breaks for carers in 2011/12.

The Group involves carers in the decision making by listening to carers at the quarterly carers' forum, an annual carers' conference and use of surveys. Nineteen projects are being funded which include carers'

²² These percentages do not add up to 100% due to rounding

relationship counselling and debt advice projects, respite breaks for older carers and a mental health carers information project.

Caroline O'Neill of NHS South West London Richmond Borough Team highlighted the valuable contribution carers make and the positive local partnerships:

"We are committed to ensuring that carers are supported, recognised and valued by both health and social care services. We are proud of our partnership approach working closely with local authority colleagues and local carer organisations to deliver for carers."

Are PCTs working with relevant local authorities?

The NHS Operating Framework also guided PCTs to work with local authorities to develop policies, plans and budgets and where appropriate to pool budgets with them.

82% of PCTs responding (92 of 112) advised that they had worked with their local authority to develop policies, plans and budgets, albeit many of these refer to joint working on outdated strategies. 16% said that this is planned for 2011/12 leaving 2% who indicated that they would not be working to produce policies, plans and budgets to support carers.

49% of PCTs advised they are pooling budgets or jointly commissioning services with local authorities. A further 29% advised that they will be discussing pooling budgets during 2011/12.

We have not surveyed local authorities to gain their view on the level of coordination between PCTs and local authorities. However, discussions with local authority representatives including Directors of Adult Social Services have indicated that they are not experiencing the level of coordination that the reported figures suggest. One local authority advised it has not been able to engage with its PCT on this issue at all, in contrast to the PCT response.

In other areas, there is multi-agency cooperation where PCTs, local authorities, carers and carers' organisations have all worked closely together. Surrey NHS and Surrey County Council are Joint Commissioners of carers' services and the Joint Carers Commissioning Strategy Group is chaired by the Chief Executive of Action for Carers (Surrey), part of The Princess Royal Trust for Carers Network.

Together they are developing a plan whereby GP practices will be able to directly refer carers for a direct payment, if GPs felt that a break or

other support would improve their health and wellbeing. There are also additional investments in community based respite via Crossroads Care Surrey and breaks for carers in End of Life situations. Approximately £1.9m will be invested in carers' services this year. The aim is to give carers like Karen in Surrey the chance of what she calls an "impossible dream".

Karen's dream – an afternoon off

"I have been a carer for 18 years and I am exhausted, over tired and stressed. Caring is a huge responsibility that consumes my life 7 days a week. A daily break for me is essential. I get help for an hour a day, five days a week. That hour enables me to do different tasks each day, like the basics, i.e. have a shower and get dressed, cook and eat a meal and sometimes have a sleep. I would like more of a break, an afternoon off every month, a few days holiday a year but when I ask social services or the NHS, I am always being made to feel like I am asking for the impossible dream!"

Conclusion

The NHS has historically been less engaged with carers' issues than social services but we cannot make the breakthrough needed in support for carers without the NHS playing a full role. This is our third report in three years looking at NHS support for carers and we do think that more PCTs are engaging with carers' organisations and funding services than before.

The additional funding made available by Governments since 2009 has made a difference even if the majority of the funding has not been used to support carers. In 2008/09, NHS Worcestershire was not funding any carers' services but then invested £120,000 in 2010/11 and is now investing £620,000 in 2011/12. We highly doubt whether this would have happened without the Government announcements, guidance and additional funding being made.

However, too many PCTs have not made the progress required to judge that the NHS has made a breakthrough in reaching an adequate level of support for carers. 37% of PCTs do not seem to have taken account of the additional funding or Government guidance, and many PCTs were starting from a very low or non-existent level of support for carers.

A breakthrough will require sustained, committed support from national Government combined with local work to assist PCTs, or successor health commissioning bodies, in their development of support for carers. We have made a start and we must keep driving forward or we will lose the progress made.

That 54% of PCTs are still in the process of developing updated policies, plans and budgets to support carers is evidence of this work in progress. Although many will publish shortly, we are disappointed that some will take more than a year from receiving the Government guidance to finalise plans.

For PCTs still working on their plans and budgets, this is an opportunity for them to follow the examples set by Sunderland, Surrey and Richmond and make a step-change in how they support carers. For this to happen though, the level and quality of engagement between PCTs and local carers' organisations must greatly improve.

The most worrying aspect of our research is that 40% of PCTs are not engaging at all with local carers' organisations to develop policies, plans and budgets. Having minimal irregular contact with or providing some funding for organisations connected to supporting carers does not equal real co-production of plans and budgets for local carers. It is not surprising

that where PCTs have made rapid progress, they have done so by involving local carers' organisations and utilising their skills and experience.

The value of investing in carers' organisations was the focus of a recent social return on investment analysis. It found that an investment of less than £5m a year in five Carers' Centres resulted in at least £73m worth of social gains a year.²³ As we have shown above, supporting carers improves their health and reduces unwanted admissions into hospital and residential care.

Just as local people will consider the actions of their local PCT, Government must remember its responsibility and commitment to carers and consider what its response should be to a failure of PCTs to implement the Carers' Strategy and NHS Operating Framework.

We call on PCTs and Government to drive progress to:

- Ensure the additional allocation of funding reaches carers
- Ensure that updated plans and budgets for supporting carers are published by October 2011.
- Ensure future plans, such as Joint Strategic Needs Assessments, highlight support and breaks for carers as a priority.
- Have every lever available to the Department of Health used to ensure that PCTs meet their responsibilities to support carers.

²³ Clifford, J, Theobald, C, Mason S (2011), The Princess Royal Trust for Carers: Social Impact Evaluation Using Social Return on Investment. London, The Princess Royal Trust for Carers.

Appendix 1 – Sample questionnaire for PCTs

Has the PCT this year worked with the relevant local authority to agree policies, plans and budgets to support carers for 2011/12?

Yes

No

Will be later in 2011/12

Have you pooled any budgets with the relevant local authority to provide services specifically for carers in 2011/12?

Yes

No

Under discussion for 2011/12

Have you worked with local carers and/or carers' organisations to agree policies, plans and budgets to provide services that specifically support carers in 2011/12?

Carers:

Yes / No

Local carers' organisation(s):

Yes / No

If possible, please list local carers' organisation(s)

Have you published and made these policies, plans and budgets available to local people?

Yes

No

Expected publication date:

If possible, please provide the web-link for publications or contact details of person who could provide them

Appendix 2 – Sample questionnaire for carers’ organisations

Q. Name of PCTs in the area you cover

Q. Has the local PCT(s) worked with you to formulate policies, plans and budgets to support carers in 2011/12?

| | PCT 1 | PCT 2 | PCT3 |
|----------------------|-------|-------|------|
| Yes | | | |
| No | | | |
| Due later in 2011/12 | | | |

Further comments:

Q. How would you grade your involvement?

| | PCT 1 | PCT 2 | PCT 3 |
|--|-------|-------|-------|
| A good example of co-production with continued discussions and opportunity for input and influence | | | |
| A reasonable example of co-production with some discussion and some consideration of input | | | |
| A poor example of co-production with little opportunity for input or influence | | | |

Further comments:

Q. Has the PCT met or spoken with carers to formulate policies, plans and budgets to support carers?

| | PCT 1 | PCT 2 | PCT 3 |
|----------------------|-------|-------|-------|
| Yes | | | |
| No | | | |
| Due later in 2011/12 | | | |
| Don't know | | | |

Further comments:

Q. Has the PCT(s) published policies, plans and budgets or do you know if they plan to?

| | PCT 1 | PCT 2 | PCT 3 |
|----------------------|-------|-------|-------|
| Yes | | | |
| No | | | |
| Due later in 2011/12 | | | |
| Don't know | | | |

Further comments:

Appendix 3 – Quotes from carers on for the importance of breaks

“I get stressed out by over doing it, and I since have a medical condition myself. The kind of break I need is just to have a couple of days away from home to have a break from my caring role.”

“I need a break to recharge my battery and feel emotionally and physically in a good frame of mind. A week away from caring maybe twice a year would be fabulous.”

“I provide 24 hours a day care for my wife who has had a stroke. A two week break every year would be nice, and help me recharge my battery.”

“I have not had a holiday for a long time and need a break to get things done at home which I can't do when my mother is there, like decorating her bedroom. Also, it would give me a chance to see friends, relax and recharge my batteries.”

“I look after my daughter solely by myself without help from a support worker. The kind of break I need is one where I can just forget about all of the worries for a bit.”

“I have cared seven days a week and 24 hours a day for the last six years. I just need a rest.”

“I am taking care of my mother who suffers from dementia, as well as having two teenage sons. A break twice a week to go out for lunch or see a friend would be good. Or maybe even a week's holiday one year.”

“The kind of break I need is – anything!”

Appendix 4 – Summary of responses for each PCT

| Primary Care Trust | Have plans & budgets for 2011/12 been published? | Joint planning with local authority (PCT view) | Pooled budgets with local authority (PCT view) | Joint planning with carers' organisations (PCT view) | Joint planning with carers (PCT view) | Level of co-production (carers' organisations view) |
|----------------------------------|---|--|--|--|---------------------------------------|---|
| NHS Ashton, Leigh and Wigan | Will not be publishing | Yes | Yes | Yes | Yes | No information |
| NHS Barking and Dagenham | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Good |
| NHS Barnet | Yes but referred to 2009–12 Strategy not updated | Yes | No | Yes | Yes | Poor |
| NHS Barnsley | Yes but referred to 2010–13 Strategy not updated | Yes | Yes | Yes | Yes | No information |
| NHS Bassetlaw | Due summer 2011 | Yes | No | No | No | No information |
| NHS Bath and North East Somerset | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Poor |
| NHS Bedfordshire | Available on request & given to Carers' Partnership board | Yes | Yes | Yes | Yes | No information |
| NHS Berkshire East | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | None |
| NHS Berkshire West | Due September 2011 | Will be later in 2011/12 | Will discuss during 2011/12 | Will be later in 2011/12 | Will be later in 2011/12 | None |
| NHS Bexley Care Trust | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | None |

| | | | | | | |
|------------------------------------|--|--------------------------|-------------------|-------------------|-------------------|----------------|
| NHS Birmingham East and North | 2008 Strategy (unpublished) still in operation | Will be later in 2011/12 | No | No | No | No information |
| NHS Blackburn with Darwen | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Reasonable |
| NHS Blackpool | Yes but referred to 2010–15 Strategy not updated | Yes | Yes | Yes | Yes | Reasonable |
| NHS Bolton | Will not be publishing | Will be later in 2011/12 | No | No | No | No information |
| NHS Bournemouth and Poole | Yes but referred to 2008–10 Strategy not updated | Yes | Under discussion | Yes | Yes | No information |
| NHS Bradford and Airedale Teaching | Due during 2011/12 | Yes | Yes | Yes | Yes | No information |
| NHS Brent Teaching | Yes but referred to 2010–14 Strategy not updated | Yes | Yes | Yes | No | None |
| NHS Brighton and Hove City | Yes but referred to 2010–12 Strategy not updated | Yes | No | Yes | Yes | Reasonable |
| NHS Bristol | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Good |
| NHS Bromley | Yes but referred to 2007 Strategy not updated | Yes | Yes | Yes | Yes | None |
| NHS Buckinghamshire | Yes but referred to 2010-13 Strategy not updated | Yes | Under discussion | Yes | Yes | None |
| NHS Bury | Yes but referred to 2009–12 | Yes | Yes | Yes | Yes | None |

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|----------------------------------|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------|--|
| | Strategy not updated | | | | | | |
| NHS Calderdale | Current 2009–12 strategy renewed in 2012 | Yes | No | Yes | No | No information | |
| NHS Cambridgeshire | Yes but referred to 2008–11 Strategy not updated | Yes | Yes | Yes | Yes | No information | |
| NHS Camden | Due autumn 2011 | Yes | Jointly commission | Yes | Yes | Reasonable | |
| NHS Central and Eastern Cheshire | Due July 2011 | Yes | No | Yes | Yes | None | |
| NHS Central Lancashire | Yes but referred to 2009–12 Strategy not updated | Yes | Jointly commission | Yes | Yes | Poor | |
| NHS City and Hackney Teaching | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Reasonable | |
| NHS Cornwall and Isles of Scilly | Due during 2011/12 | Yes | Under discussion | Yes | Yes | No information | |
| NHS County Durham | Yes but referred to 2009–13 Strategy not updated | Yes | Yes | Yes | Yes | No information | |
| NHS Coventry | Due during 2011/12 | No | No | Yes | Yes | Poor | |
| NHS Croydon | Yes but referred to 2008–11 Strategy not updated | Yes | Yes | Yes | Yes | Poor | |
| NHS Cumbria | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Reasonable | |
| NHS Darlington | No information in response | No information in response | No information in response | No information in response | No information in response | No information | |

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| NHS Derby City | Will not be publishing | Yes | Under discussion | Yes | Yes | Good |
| NHS Derbyshire County | Will not be publishing | Will be later in 2011/12 | Will discuss during 2011/12 | Yes | Yes | Reasonable |
| NHS Devon | Due July 2011 | Yes | Under discussion | Yes | Yes | Good |
| NHS Doncaster | Will not be publishing | No | No | Yes | Yes | No information |
| NHS Dorset | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | No information |
| NHS Dudley | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Good |
| NHS Ealing | Due during 2011/12 | Yes | Under discussion | Yes | Yes | No information |
| NHS East and North Hertfordshire | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | No information |
| NHS East Lancashire | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Good |
| NHS East Riding of Yorkshire | Due during 2011/12 | Yes | Yes | Yes | Yes | No information |
| NHS East Sussex Downs and Weald | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | None |
| NHS Eastern and Coastal Kent | Due during 2011/12 | Yes | Under discussion | Yes | No | None |
| NHS Enfield | Due 01/10/2011 | Yes | Under discussion | No | Yes | None |
| NHS Gateshead | Due during 2011/12 | Yes | Yes | Yes | Yes | Good |
| NHS Gloucestershire | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Good |
| NHS Great | Due 01/04/2012 | Yes | Under | Yes | Yes | Good |

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|-------------------------------------|------------------------|--------------------------|-----------------------------|-------------------|-------------------|----------------|
| Yarmouth and Waveney | | | discussion | | | |
| NHS Greenwich Teaching | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | No information |
| NHS Halton and St Helens | Due July 2011 | Will be later in 2011/12 | Will discuss during 2011/12 | Yes | Yes | Good |
| NHS Hammersmith and Fulham | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | No information |
| NHS Hampshire | Due 2011/12 | Will be later in 2011/12 | Will discuss during 2011/12 | Yes | Yes | No information |
| NHS Haringey | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | No information |
| NHS Harrow | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | No information |
| NHS Hartlepool | Published | Yes | No | No | No | No information |
| NHS Hastings and Rother | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | No information |
| NHS Havering | Will not be publishing | Will be later in 2011/12 | No | No | No | None |
| NHS Heart of Birmingham | Due summer 2011 | Will be later in 2011/12 | Will discuss during 2011/12 | Yes | Yes | No information |
| NHS Herefordshire | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Good |
| NHS Heywood, Middleton and Rochdale | Due during 2011/12 | Yes | Under discussion | Yes | Yes | No information |
| NHS Hillingdon | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | None |
| NHS Hounslow | Awaiting | Awaiting | Awaiting | Awaiting | Awaiting | No |

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| | response | response | response | response | response | information |
| NHS Hull Teaching | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | No information |
| NHS Isle of Wight | Yes but referred to 2009–12 Strategy not updated | Yes | Yes | Yes | Yes | No information |
| NHS Islington | Due during July 2011 | Yes | No | Yes | Yes | None |
| NHS Kensington and Chelsea | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | No information |
| NHS Kingston | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | None |
| NHS Kirklees | Yes but referred to 2010–15 Strategy not updated | Yes | Jointly commission | Yes | Yes | No information |
| NHS Knowsley | Due during 2011/12 | Yes | Yes | Yes | Yes | Reasonable |
| NHS Lambeth | Due during 2011/12 | Yes | Yes | Yes | No | Reasonable |
| NHS Leeds | Due during 2011/12 | Yes | Under discussion | Yes | Yes | No information |
| NHS Leicester City | Due during 2011/12 | Yes | No | Yes | No | None |
| NHS Leicestershire County and Rutland | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | None |
| NHS Lewisham | Due during 2011/12 | Yes | Jointly commission | Yes | No | None |
| NHS Lincolnshire Teaching | Due during 2011/12 | Yes | Under discussion | Yes | No | None |
| NHS Liverpool | Awaiting | Awaiting | Awaiting | Awaiting | Awaiting | Poor |

| | response | response | response | response | response | response |
|---|--|--------------------------|-----------------------------|--------------------------|-------------------|----------------|
| NHS Luton | No publication | Will be later in 2011/12 | Will discuss during 2011/12 | No | No | No information |
| NHS Manchester | Due July 2011 | Will be later in 2011/12 | No | Yes | Yes | No information |
| NHS Medway | Due July 2011 | Yes | Under discussion | Yes | Yes | Good |
| NHS Mid Essex | Due during 2011/12 | Will be later in 2011/12 | Jointly commission | Will be later in 2011/12 | No | Good |
| NHS Middlesbrough | Will not be publishing | Yes | Yes | No | No | No information |
| NHS Milton Keynes | Due end 2011 | Yes | Yes | Yes | Yes | No information |
| NHS Newcastle | Due during 2011/12 | Will be later in 2011/12 | Will discuss during 2011/12 | No | No | None |
| NHS Newham | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | No information |
| NHS Norfolk | Published | Yes | Yes | Yes | Yes | Good |
| NHS North East Essex | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Reasonable |
| NHS North East Lincolnshire Care Trust Plus | Yes but referred to 2009–12 Strategy not updated | Yes | Yes | Yes | Yes | No information |
| NHS North Lancashire | Yes but referred to 2009 Strategy not updated | Yes | No | Yes | Yes | No information |
| NHS North Lincolnshire | Due during 2011/12 | Yes | No | Yes | No | No information |
| NHS North | Due June 2011 | Yes | Yes | Yes | Yes | Reasonable |

Somerset

| | | | | | | |
|-------------------------------|--|--------------------------|-----------------------------|--------------------------|--------------------------|----------------|
| NHS North Staffordshire | Due during 2011/12 | Yes | Yes | No | Yes | No information |
| NHS North Tyneside | Due during 2011/12 | Will be later in 2011/12 | Will discuss during 2011/12 | No | No | None |
| NHS North Yorkshire and York | Due by Nov 2011/12 | Yes | Jointly commission | Yes | Yes | No information |
| NHS Northamptonshire | Due by Aug 2011/12 | Yes | Yes | Yes | Yes | Good |
| NHS Northumberland Care Trust | Due during 2011/12 | Will be later in 2011/12 | Will discuss during 2011/12 | No | No | Reasonable |
| NHS Nottingham City | Yes but 2008–11 Strategy not updated | Yes | No | Yes | Yes | Good |
| NHS Nottinghamshire County | No publication | Will be later in 2011/12 | No | Will be later in 2011/12 | Will be later in 2011/12 | Good |
| NHS Oldham | Due during 2011/12 | Yes | Under discussion | Yes | Yes | None |
| NHS Oxfordshire | Yes but referred to 2009–12 Strategy not updated | Yes | Yes | Yes | Yes | None |
| NHS Peterborough | Due 01/11/2011 | Will be later in 2011/12 | Will discuss during 2011/12 | Yes | Yes | No information |
| NHS Plymouth | Due July 2011 | Yes | Under discussion | Yes | Yes | No information |
| NHS Portsmouth City | Published | Yes | Yes | Yes | Yes | No information |
| NHS Redbridge | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | No information |
| NHS Redcar and | Will not be | Yes | Yes | No | No | No |

| | | | | | | | |
|-----------------------------|--|-------------------|-------------------|-------------------|-------------------|-------------------|----------------|
| Cleveland | publishing | | | | | | information |
| NHS Richmond and Twickenham | Due July 2011 | Yes | Yes | Yes | Yes | Yes | Good |
| NHS Rotherham | Yes but referred to 2010 Strategy not updated | Yes | No | Yes | Yes | Yes | No information |
| NHS Salford | Due during 2011/12 | Yes | Yes | Yes | Yes | Yes | Good |
| NHS Sandwell | Due 31/08/2011 | Yes | Under discussion | Yes | Yes | Yes | None |
| NHS Sefton | Due September 2011 | Yes | Yes | Yes | Yes | No | Good |
| NHS Sheffield | Yes but referred to 2010–13 Strategy not updated | Yes | No | Yes | Yes | Yes | No information |
| NHS Shropshire County | Published | Yes | Yes | Yes | Yes | Yes | No information |
| NHS Solihull Care Trust | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | No information |
| NHS Somerset | Due July 2011 | Yes | Under discussion | Yes | Yes | Yes | No information |
| NHS South Birmingham | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | No information |
| NHS South East Essex | Due during 2011/12 | Yes | Under discussion | Yes | Yes | Yes | No information |
| NHS South Gloucestershire | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Reasonable |
| NHS South Staffordshire | Due during 2011/12 | Yes | Yes | Yes | Yes | Yes | Reasonable |
| NHS South Tyneside | Due during 2011/12 | Yes | Yes | Yes | Yes | Yes | Good |
| NHS South West | Due during | Yes | Yes | Yes | Yes | Yes | Poor |

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|-------------------------------|--|-------------------|--------------------|-------------------|-------------------|----------------|--|
| Essex | 2011/12 | | | | | | |
| NHS Southampton City | Due during 2011/12 | Yes | Yes | Yes | Yes | No information | |
| NHS Southwark | Produced but will not be published | Yes | Yes | Yes | Yes | No information | |
| NHS Stockport | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Poor | |
| NHS Stockton-on-Tees Teaching | Published | Yes | No | No | No | No information | |
| NHS Stoke on Trent | Published | Yes | No | Yes | Yes | No information | |
| NHS Sunderland | Due July 2011 | Yes | Yes | Yes | Yes | Good | |
| NHS Suffolk | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | None | |
| NHS Surrey | Due during 2011/12 | Yes | Yes | Yes | Yes | Good | |
| NHS Sutton and Merton | Yes but referred to 2010-13 Strategy not updated | Yes | Jointly commission | Yes | Yes | None | |
| NHS Swindon | No publication | Yes | Yes | Yes | Yes | None | |
| NHS Tameside and Glossop | Due 01/07/2011 | Yes | Yes | No | No | No information | |
| NHS Telford and Wrekin | Due during 2011/12 | Yes | Under discussion | Yes | Yes | No information | |
| NHS Torbay Care Trust | Due 31/08/2011 | Yes | Yes | Yes | Yes | No information | |
| NHS Tower Hamlets | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | None | |
| NHS Trafford | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Good | |

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|------------------------|---|--------------------------|-----------------------------|-------------------|-------------------|----------------|
| NHS Wakefield District | Due 31/08/2011 | Will be later in 2011/12 | No | No | Yes | No information |
| NHS Walsall Teaching | Yes, but could not refer to strategy or find online. Judged to be no. | Yes | Yes | Yes | Yes | No information |
| NHS Waltham Forest | Yes but referred to 2010–15 Strategy not updated | Yes | Yes | Yes | Yes | None |
| NHS Wandsworth | Yes but referred to 2009–14 Strategy not updated | Yes | Yes | Yes | Yes | Reasonable |
| NHS Warrington | Due during 2011/12 | Yes | Yes | Yes | Yes | None |
| NHS Warwickshire | Will not be publishing | Will be later in 2011/12 | Will discuss during 2011/12 | No | No | No information |
| NHS West Essex | Published | Yes | Under discussion | Yes | Yes | No information |
| NHS West Hertfordshire | Not surveyed | Not surveyed | Not surveyed | Not surveyed | Not surveyed | No information |
| NHS West Kent | Yes but referred to 2009 Strategy not updated | Yes | Yes | Yes | Yes | Reasonable |
| NHS West Sussex | Due during 2011/12 | Yes | Yes | Yes | Yes | Reasonable |
| NHS Western Cheshire | Yes but refers to a strategy not updated | Yes | No | Yes | Yes | None |
| NHS Westminster | Awaiting response | Awaiting response | Awaiting response | Awaiting response | Awaiting response | No information |
| NHS Wiltshire | Due during | Yes | Under | Yes | Yes | None |

| | 2011/12 | | discussion | | | |
|------------------------|---|-----|------------------|-----|-----|----------------|
| NHS Wirral | Current strategy being reviewed | Yes | Yes | Yes | Yes | None |
| NHS Wolverhampton City | Yes but refers to 2010 Strategy not updated | Yes | Under discussion | Yes | Yes | No information |
| NHS Worcestershire | Published | Yes | Yes | Yes | Yes | No information |

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Registered in England no. 1544708

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