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# **Personal Health Budgets: Experiences and outcomes for budget holders at nine months**

## **Fifth Interim Report**

**Jacqueline Davidson, Kate Baxter,  
Caroline Glendinning, Karen Jones,  
Julien Forder, James Caiels,  
Elizabeth Welch, Karen Windle,  
Paul Dolan and Dominic King**

**DH 2523**

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This is the fifth in a series of five interim reports. The final report of the evaluation is due in October 2012.

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## Glossary of Abbreviations

COPD	Chronic Obstructive Pulmonary Disease
CRB	Criminal Records Bureau
IB	Individual Budget – piloted in social care between 2006 and 2008 and intended to include multiple funding streams including Access to Work, Supporting People, Independent Living Fund, Equipment Services and Disabled Facilities Grant
LTNC	Long-Term Neurological Condition
NHS	National Health Service
PA	Personal assistant
PCT	Primary Care Trust - until 2013 the NHS organisations responsible for piloting personal health budgets



## Executive Summary

Fifty-two people with long-term health problems were interviewed nine months after being offered a personal health budget, as were 13 carers of budget holders three and nine months after the offer of a budget. Together they were drawn from 17 of the Primary Care Trusts (PCTs) that are currently piloting personal health budgets in England.

These interviews suggest there is widespread potential for personal health budgets to lead to improvements in health and well-being. However, these benefits risked being reduced by delays and other problems in implementing personal health budgets.

### The benefits of personal health budgets

Most interviewees said that the personal health budget had improved their health. The benefits often extended beyond the specific condition for which the budget had been given and sometimes also exceeded initial expectations. Thus people given a budget because of long-term physical health problems also reported improvements in their mental health. People given a budget because of mental health problems reported greater well-being, less stress, reduced use of emergency services and better management of relapses. People receiving a budget because of their eligibility for NHS Continuing Healthcare appreciated being able to choose who provided their care and reported greater continuity of care.

Personal budget holders and carers appreciated having greater choice and

control over aspects of their health care and greater flexibility so they could arrange services to suit them. They also appreciated being able to access services and goods that were not normally available through the NHS. Having a personal health budget had encouraged some to take other steps to improve their health, for example taking more exercise. Increased self-confidence, a better social life, reduced use of GP services and prescriptions and better relationships with health professionals were among the other reported benefits.

Personal health budgets could have wider family benefits too. As budget holders' health improved, they reported needing to rely less on family carers; less anxiety and stress on the part of relatives; and increased ability to take part in family activities. Carers also reported direct benefits when personal health budgets reduced the amount of care they had to give and indirect benefits from seeing improvements in the well-being of the person they supported.

On the whole, interviewees felt comfortable making choices about their health; most thought they were best placed to know their own needs and what would make them feel better. A minority would have liked more professional advice, for example about what might benefit their condition or in choosing the best service provider.

### What personal health budgets were used for

The most common uses of personal health budgets among these

interviewees were for employing carers or personal assistants to provide support in the home, physical exercise, and complementary or alternative therapies. Less common uses included home delivery of frozen meals, computers, wheelchairs and other equipment, and social activities.

## Challenges in implementing personal health budgets

Interviewees were among the first to be offered personal health budgets so their experiences may not be typical. However they provide valuable insights into the challenges of implementing personal health budgets, should these be extended beyond the current pilot phase. There were a number of areas in which interviewees reported problems and delays; sometimes the resulting anxiety and stress threatened the positive benefits of the budget.

### Information and transparency

Most interviewees were happy with the advice and help they had received to plan their care/support, particularly information about the options open to them and examples of how people in similar circumstances had used a personal health budget. Access to clinical advice on the suitability of a particular service or item of equipment early in the care/support planning process was particularly helpful for some interviewees.

However, even nine months after the offer of the budget, a minority of interviewees did not know whether they had a budget in place, the size of the budget, how much had been spent so far or how much was left for the rest of the year. Some did not understand that the budget was a personalised funding allocation and thought it came from a

collective 'pot' for which they had to compete with others; this inhibited them from requesting some items they needed.

A widespread area of uncertainty was about what personal health budgets could and could not be used for. A minority remained confused about what their budget was funding, or found their budget was being used to pay for things they did not remember asking for or think they needed. Around a fifth of interviewees had had plans for using their budget turned down by PCT staff or panels that 'signed off' budget care/support plans, but received no clear guidelines as to what were or were not permitted uses. Moreover, there appeared to be differences between PCTs in what personal health budgets were allowed to be used for, particularly whether budgets had to be limited to narrow health-related uses or could be used for wider well-being gains. Having budget plans turned down caused disappointment and frustration and made people reluctant to make new requests.

Few interviewees had a clear idea of the future of their personal health budget beyond the first year. This caused considerable anxiety, particularly when the budget had already led to significant gains in health and well-being.

### Delays in approving care/support plans and getting services in place

Getting approval for care/support plans by a PCT panel could be protracted, ranging from a few weeks to eight months. Many people found care/support planning a positive and encouraging experience, so such delays could cause disappointment and distress. This was particularly the

case for people eager to start a new treatment or therapy that they anticipated would benefit them.

Delays could also be experienced in getting approved items or services in place, particularly where these were procured by the PCT. Delays could lead to people purchasing items themselves and being out-of-pocket, taking risks with unsuitable equipment, or having to rely on family members to fill gaps in care.

The reasons for these delays were not always clear; interviewees were not kept routinely informed of progress and some could not find anyone who knew about the status of their care/support plan.

### **Managing the personal budget**

Interviewees' budgets were either managed by the PCT/another third party, or by themselves/their carer as a direct payment. PCT management avoided the additional responsibilities of managing direct payments, but could leave interviewees feeling they were not trusted to manage the budget themselves. PCT management also risked delays in procuring services, paying subscriptions or reimbursing out-of-pocket expenses. Some people who had initially opted for PCT management would with hindsight have preferred a direct payment.

Those who had opted for direct payments were generally happy with this and appreciated receiving help with recruiting and employing paid carers.

### **Reviews**

Few interviewees knew whether they had had a formal or informal review, but valued enormously any contact from PCT staff once their budget was

in place. This contact provided reassurance and helped sustain motivation, for example to continue with agreed exercise programmes.

### **Personal health budgets and social care**

Some budget holders and carers also received social care funding, either as a separate personal budget or as a contribution to NHS Continuing Healthcare-funded support. There was little evidence of the two funding streams being integrated and some carers reported protracted delays as local NHS and social care departments disputed which budget should fund particular items.





# 1. Introduction

## 1.1 Background – personal health budgets

Personal health budgets are central to the development of more personalised health care in England. The overarching aim of personalisation is to create a more patient-centred, responsive NHS (Department of Health, 2009). The contribution of personal health budgets to this broader transformation, and the Government's commitment to the policy, was restated in the NHS White Paper *Equity and Excellence: Liberating the NHS* (Department of Health, 2010) and further reiterated in the Government's response to the report of the NHS Future Forum (Department of Health, 2011).

Personal health budgets aim to give individuals more choice about the services and support they receive, by giving them greater control over money that is spent on their health care (but excluding primary and emergency care). The recommended process for receiving a personal budget is that, after an assessment of needs, an individual is told how much money is available to them and draws up plans for using the budget in ways that are intended to benefit their health and well-being. Plans for using the budget are agreed with and signed off by the Primary Care Trust (PCT), after assessment by a panel or board for possible clinical and other risks. The personal health budget money can be held and managed by a health professional; held by another third party on behalf of the patient; taken as a cash direct payment held by the patient; or as a combination of these.

In 2009, the Department of Health invited PCTs to become pilot sites for personal health budgets. Between them, the pilot sites are offering personal health budgets to people with a range of long-term conditions including diabetes, lung diseases, mental health problems, stroke, long-term neurological conditions (LTNCs) or those eligible for NHS Continuing Healthcare. Pilot sites were free to decide how to design personal health budgets in their area, and different sites have taken different approaches. For example, some sites have used personal health budgets to try to redesign whole pathways of care for a particular condition, as an alternative to existing services. Other sites have offered patients a personal budget in addition to their existing services, to pay for preventative interventions, such as gym membership. Personal health budgets are also being piloted in one PCT for maternity care and in a few PCTs for end-of-life care.

## 1.2 The evaluation of the personal health budget pilots

Personal health budgets are new to the NHS and involve major cultural and organisational changes for services, professionals and patients. Evaluating the pilot projects is therefore very important. The final report of the evaluation will be published in Autumn 2012 and the Government will use the results of the evaluation to inform decisions about the subsequent wider roll-out of the initiative. Twenty of the PCTs piloting personal health budgets are participating in an in-depth evaluation of the programme, with the other pilot sites contributing to a less detailed evaluation. The in-depth evaluation is examining the impacts of personal health budgets on

budget holders, carers and the wider NHS; it will also examine the use of personal health budgets in maternity and end-of-life care.

The overall aims of the evaluation are to identify whether personal health budgets deliver better outcomes for patients than conventional health services and, if so, how they should best be implemented (for full details see [www.phbe.org.uk](http://www.phbe.org.uk)). An important strand of the evaluation, reported here, examines in-depth the experiences of subsamples of patients and carers offered personal health budgets. This strand of the evaluation involves semi-structured interviews with small samples of patients and carers conducted around three months after accepting the offer of a personal health budget and again six months later. An earlier interim report (Irvine *et al.*, 2011) described patients' early experiences of personal health budgets, derived from the interviews with budget holders three months after the offer of a personal health budget. This report presents findings from the nine-month interviews with budget holders, and from the three- and nine-month interviews with carers.

The interviews with budget holders nine months after accepting the offer of a personal health budget covered:

- The impacts of the personal health budget on the health, well-being and quality of life of the budget holder (and other family members).
- How the personal health budget had been used and budget holders' reflections on the choices they had made.
- Budget holders' satisfaction with the level of their personal health budget.
- Reflections on the chosen management options for the personal health budget.
- Experiences of the implementation of personal health budgets.

The recruitment of carers to the evaluation began too late for their experiences to be included in the earlier interim report. The experiences of carers of personal health budget holders, derived from both their three- and nine-month interviews, are therefore included in this report. These carers were supporting budget holders who were not part of the main evaluation; their experiences of personal health budgets to some extent extend the accounts of the budget holder sample. However, the focus here is specifically on their experiences as carers, including:

- Carers' involvement in the decision to try a personal health budget.
- Carers' roles in planning how the personal health budget would be used and managed.
- The extent to which carers anticipated, and actually derived, benefits for themselves from the budget.
- Implementation experiences that impacted on their care-giving roles.

## **1.3 The personal health budget holders and carers in this report**

### **1.3.1 Personal health budget holders**

Table 1.1 gives the numbers of budget holders interviewed around three and nine months after the offer of a personal health budget.

**Table 1.1 Numbers of budget holders interviewed**

<b>Condition</b>	<b>3 months</b>	<b>9 months</b>
COPD	7	6
Diabetes	6	5
LTNC	13	10
Mental health	9	8
NHS Continuing Healthcare	15	15
Stroke	8	8
<b>Total</b>	<b>58</b>	<b>52</b>

The 52 budget holders were at different stages with their personal health budgets. About a fifth had no budget in place at the time of the nine-month interviews; around two-thirds had had services and support funded through the budget in place for at least three months (Table 1.2).

**Table 1.2 Length of time personal health budget in place**

<b>Length of time budget in place</b>	<b>Number of budget holders</b>
No personal health budget in place	9
Personal health budget services in place less than 3 months	5
Personal health budget services in place between 3 and 6 months	11
Personal health budget services in place more than 6 months	25
Personal health budget terminated*	1
Budget holder not sure if personal health budget in place	1

\* Budget holder terminated budget in consultation with PCT because health had improved.

### 1.3.2 Carers of personal health budget holders

The initial aim was to conduct semi-structured interviews with 20 carers of personal health budget holders, at three and nine months after the offer of a budget. However, only 19 could be recruited within the available timeframe. Five of these carers subsequently withdrew from the personal health budget pilot before the nine-month interview and a sixth who had been interviewed at three months could not be recontacted at nine months.

**Table 1.3 Number of carers interviewed**

<b>Carers who were supporting relatives with:</b>	<b>3 month interview</b>	<b>9 month interview</b>
Stroke	3	1
COPD	2	1
LTNC	7	4
NHS Continuing Healthcare	7	7
<b>Total</b>	<b>19</b>	<b>13</b>

Because this report focuses specifically on the impacts and outcomes of personal health budgets, only the accounts of the 13 carers who took part in both interviews are included. The carers were mainly caring for budget holders eligible for NHS Continuing Healthcare or with long-term neurological conditions.

Further details of the recruitment processes and samples are contained in Appendix A.

## 1.4 Structure of the report

The next section of this report details the impact of personal health budgets on the health and well-being of budget holders nine months after the offer of the budget. Section 3 details how they used their personal health budgets; their reflections, with hindsight, on the choices they made; and any (further) changes they would like to make. This is followed by (Section 4) budget holders' views on the level of their budget; and their experiences of the arrangements for managing their personal health budget (Section 5). Section 6 details budget holders' experiences of the implementation of the pilots, including the information, advice and support they received, experiences of securing their desired services or equipment, and the interface with any social care support they also received. Section 7 focuses on the experiences and outcomes of a small sample of carers of people offered personal health budgets. Section 8 discusses the findings and their implications for the wider roll-out of the initiative.

The patients and carers participating in the interviews reported here were recruited to the evaluation early in the implementation of the pilots and include some of the first patients to be offered personal health budgets. The sample included members of all the main patient/disease groups being offered personal health budgets in the pilots and was drawn from 17 of the 20 PCTs involved in the in-depth evaluation. However, it was not intended to be representative of all those offered personal health budgets. Consequently, some of the experiences reported here may not be typical once the pilots were fully operational, nor when personal health budgets are rolled out beyond the pilot stage. In the main this report also avoids giving numbers or proportions of people who reported particular experiences; because the sample was not representative, no inference can be made about the overall prevalence of any specific experience.

The experiences reported here will be complemented by the full report of the evaluation, particularly evidence on the costs and outcomes of personal health budgets compared with standard NHS care; this will be published during Autumn 2012. Nevertheless, the experiences reported here provide valuable learning and feedback, both for the PCTs involved in the pilots and for other localities once personal health budgets are rolled out more widely.

## 2. Impacts of Personal Health Budgets

This section considers the impacts of the personal health budgets. First it highlights the main impacts of the budget as perceived by the study participants. It then considers more specific impacts on: health conditions; other family members; the use of services; and relationships with health professionals. The section concludes with budget holders' overall feelings about the impact of the personal health budget and their experiences of choice, control and flexibility.

It is worth noting here that some of the people who perceived (very) positive impacts of their personal health budget, may nevertheless have had very frustrating experiences with the implementation of the budget (see Section 6).

### 2.1 Main impacts of the personal health budgets as perceived by budget holders

In the nine-month interviews, budget holders were asked what they felt the main impacts of the personal health budget had been for them. Around a fifth of respondents said that having greater choice and flexibility in their health care arrangements arising from the personal health budget had been the most important impact. A good proportion of these people were receiving a budget for NHS Continuing Healthcare and valued, for example, being able to choose their own carers, when care was provided and the timing of appointments more generally:

It's made a massive difference to me [ ] being able to tell the carers when I want them to come and how long I want them to stay [ ]; it's a massive difference.

Some people said that the personal health budget had been life-changing for them, for example, by improving their health and outlook on life.

A few people said that the services received through the personal health budget had given them motivation to do more for themselves to increase their well-being, for example, to exercise more frequently. For other people the main impact had variously been: improved confidence; improved social life; access to goods and services not available on the NHS that they would otherwise have been unable to afford or had previously been paying for privately; and the opportunity to use alternative therapies. A few people said that the extra information they had got from professionals (a dietician, for example) in the course of planning how to use the budget had been the most useful impact for them.

A small minority of respondents said that the personal health budget had not had any impact. This lack of impact appeared to reflect situations in which interviewees still did not understand what the PHB was about or what progress was being made with implementing their budget; other problems with the implementation of the PHB; and, in one case, preferring their previous package of care.

### 2.1.1 Impacts on health

The majority of budget holders, when asked, said that the personal health budget had had a positive impact on their health. These improvements were reported by budget holders in all of the health condition groups in the study sample.

It was common for people to report a number of improvements to their health and well-being, not just improvements to the specific health condition for which the budget had been allocated to them. It was also not unusual for people who had been given the personal health budget for a mental health condition to report improvements in their physical health, and vice versa; people who were given the budget for physical conditions reported improvements in their mental health. For example, people who had been given the budget to improve their mobility often reported that becoming fitter (from gym membership, using their scooter), had also improved their general health and had had the knock-on effect of improving their mental health (due to getting out and about more, losing weight, increasing their motivation and confidence) as well. Perhaps not surprisingly then, some of these people reported that their overall health had benefited greatly from the personal health budget:

Massive improvement [ ] not only do I feel improved, I've got my confidence back. [ ] Now 12 months ago [ ] can't give it time, can't be bothered with all that rubbish [ ] I'd lost [ ] not only my motivation ... confidence [ ] everything, but now I've got it all back.

Some people reported reductions in pain and improvements in their ability to manage pain. For other people, the equipment obtained through their personal health budget had made the administration of their medication more efficient.

People given a personal health budget specifically for a mental health condition reported improvements in well-being; stress levels; managing their condition on a day-to-day basis; their use of emergency services for crisis episodes and in preparing for episodes of ill health:

I still have the depression and I still have anxiety but they're a lot less now. I feel I can prepare for those things [ ] I can do that now; instead of just sitting around and waiting for it to happen I can do things, not, not necessarily to prevent it but to make them a lot easier.

Some people receiving a personal health budget because they were eligible for NHS Continuing Healthcare reported that they felt better knowing that they could choose their own carers and, in so doing, had more continuity of care and more control over who came into their home to care for them and when.

A few of the study participants gave more mixed accounts of the impact of the personal health budget on their health. Examples include peoples' mental health not improving by as much as they had hoped; and services being obtained through the personal health budget simply maintaining progress made (partly through private arrangements) before the budget had come into place. Another view was that the budget would have a positive impact on people's health once the services they were accessing had a chance to bed in.

A small minority of people did not think the personal health budget had had a positive impact on their health. Examples included no improvement in their diabetes; a deterioration in mental health (which they perceived would have happened anyway, regardless of the budget); and the perception that the (stroke) services purchased with the budget would have been the same as those that would have been used without a budget.

### **2.1.2 Whether the impact of the personal health budget matched with expectations**

For some people, the impact of the personal health budget on their health had been greater than they had expected. This could be the case, for example, where someone's mental health had also improved as a result of improvements in their physical condition. One person who was able to increase his social interaction by getting out and about on the motorised scooter bought with his budget reported that he was subsequently less depressed. Similarly, a wheelchair user recounted the (unforeseen) social interaction benefits of a new laptop computer (purchased so that he could improve his speech and language) because he was now able to travel virtually around the (physically inaccessible) homes of friends and relatives by using Skype.

Other people reported that they had not anticipated how good they would feel when they had control over how they managed their health. For example, one person who had purchased a season ticket to football matches reported that this had done him a 'world of good'; by improving his mental health, giving him confidence to mix with people and fostering social relationships. He contrasted his current feelings of having hope for the future (for employment, independent living) with those before the personal health budget, when he had been taking pills prescribed by the GP, had nothing to look forward to in life and could not afford to take part in many social activities. Another person given a personal health budget for a mental health condition reported that the impacts had been greater than expected because the services funded through the budget had enabled her to better manage her mental health on a day-to-day basis and take more responsibility for managing her mental health. Another person with a mental health condition said that the personal health budget was helpful because, in planning for its use, he had been encouraged to focus on what would make him feel better and this had made him feel more positive: *'I just think it encourages me to look more positively at my health condition than [ ] otherwise I would have done'*.

A few people said that the impacts of the personal health budgets had been what they had expected or hoped for. Other people said that they had not known what to expect from the personal health budget and so were not able to say whether the impacts on their health had been more or less than they would have expected.

### **2.1.3 Impact of the personal health budget on receipt of health and other services**

A minority of people reported that their use of health and other services had declined since using the services and goods funded by their budgets. For example, one person estimated that his visits to GPs and hospital consultants had reduced



dramatically because of the large amount of weight he had lost and the general improvement in his health after exercising more frequently at the gym:

Reductions in attending doctors ... hospital visits and medication. All have gone down [ ]. The way I've looked at it [ ] I've cut my ... doctors' attendances by something like eighty per cent.

Another man similarly reported less use of medications and fewer visits to his GP. Other people in the study group reported less use of emergency services and less need for emergency out of hours social work services because their mental health was more stable. One other person thought that the use of the services funded through their budget would, in the long run, lessen their use of medical services because their health would be better maintained.

Some people had been prompted to access more services as a result of having a personal health budget. For example, one person had been prompted to apply for the higher rate of Disability Living Allowance, and others had been prompted to visit their GPs for medications that they needed.

Notwithstanding the examples above, the majority of budget holders said that the goods and services being funded through the personal health budget had not so far had any impact on their use of health or other services. In some cases this was because budget holders had not previously used any other services before getting a personal health budget.

#### **2.1.4 Impacts on relationships with health professionals**

Around half of the budget holders did not think that the personal health budget had had any impact on their relationships with health professionals. In some cases, this could be because they did not actually have any on-going contacts with health professionals.

Other budget holders reported some impact on their relationships with health professionals. For example, one person said that his relationship with his social worker had improved because he now felt that he wanted to talk about his mental health. Some other people said that they appreciated the improved continuity from seeing the same professional every time or that their confidence in dealing with professionals had improved. For example, one person thought that better knowledge of his condition, which would come from having contact with a specialist physiotherapist, would improve his interactions with specialists in the future.

#### **2.1.5 Impacts on family relationships**

Positive impacts from the personal health budget on family members (and sometimes friends) were reported by the majority of budget holders. A number of participants said that, because their health had improved, so had their relationships with their partner or spouse. This was because they were able to do more things as a family and because their partners (and indeed, other family members) now worried less about them because they were getting beneficial treatment and services. In

many cases, budget holders reported that their family members' well-being had also improved from seeing improvements in the budget holder's health and well-being:

Me kids and me partner [ ], he can go to work knowing that I'm, I'm happy and safe and what have you. So I suppose his mind's at [ ] ease a little bit more as well. So it has a knock-on effect don't it really? You know, if I'm all right then everybody's all right, so to speak, aren't they?

There were also reported improvements for family members when they were able to reduce the amount of informal care they gave to the budget holder, so freeing up (more of) their time: *'well it's made a difference to the wife, she doesn't have to do so much for me now as she did [ ] and I can do more (for her) [ ] which helps'*. This was sometimes accompanied by a reduction in stress for the family member(s) concerned, where they were able to access respite, for example, or sleep through the night because alternative care arrangements had been put in place.

For some budget holders the services funded through the personal health budget they now used had increased the amount of time they spent with friends or had widened their friendship networks.

A small number of budget holders could not think of any impact of the personal health budget on their family or social networks.

## 2.2 Experiences of choice, control and flexibility

As noted in the Introduction, one of the main policy aims of personal health budgets is to increase the choice and control that people have over their health care. The majority of interviewees said that they perceived the personal health budget had increased the level of choice and control they had over their health care. Choices were enhanced for people in the types of services that could now be used (for example, gym membership, physiotherapy, alternative therapies, employing carers they wanted) and from giving people funds to allow them to choose services. Factors such as these appeared to give people greater feelings of control over their health care:

I've been able to choose something that I think might be beneficial, whether it transpires to be so or not has yet to be seen. But at least I've been given the opportunity to take control of some of the health care issues available to me. I had a choice.

Some people also felt more in control of their health condition and in deciding what would make them feel better:

I'm able to choose things that, that I feel might benefit me more than just more medication; you're able to do different things that are outside of the box.

Another person noted that a hospital consultant would have been unlikely to have prescribed a personal assistant for him.

People also felt that they had (greater) flexibility in being able to decide how their budget was spent; in being able to change their mind if they did not like the provider;

in being able to try non-NHS services; and in being able to arrange their personal care and appointments at times to suit themselves.

Some people had mixed feelings about whether the budget had allowed them increased control, choice and flexibility. One person made the point, for example, that whilst he had more choice and flexibility over his health care, the condition itself was hard to improve: *'you've got a budget [ ] which gives you flexibility, but it's never going to change my health condition [ ]; it can't improve the condition itself'*. Another person said that they had increased control, but only over one aspect of their health care.

Other people made the point that their choices had been curtailed because the preferred use of their budget had been refused by a panel, or because desired services were not available in their area. Similarly, control over budgets could be reduced by third party management, or by lack of funds in the personal health budget.

A minority of people thought that they had no more control with a personal health budget than they had under their previous health care arrangements.

### 2.2.1 Comfort with making choices

People were asked how comfortable they were about making choices for themselves about their health care. The majority of budget holders reported being very comfortable in making such choices for themselves. A common theme was that people felt themselves best placed to know their own needs and what would make them feel better: *'it's my life [ ] and I think you should be in charge of what's, what's going to take place and what's going to happen'*. These people sometimes said that they had always been independent, or had been very clear in knowing what would help them: *'I've always made my own choices about medication. I've very often refused medication'*. In one or two cases people had relatively in-depth medical knowledge from (previous) careers as doctors or nurses. A couple of people in this group also said, however, that they wanted, or would value, professional back-up with help or information in making decisions. Another person noted that she felt comfortable making decisions precisely because the decisions were not about medications, for which she would want her GP's opinion. One or two people reported that they had been a little daunted at first in making choices about their health care but that, once they had started, it *'opened a new world ... to make my own decisions'*.

A few people in the study sample were less comfortable making choices about their health care. For example, one man who had wanted a choice of service provider, and had been attracted to the personal health budget because it offered him precisely that, had in reality found it difficult to know which provider to choose, feeling that he needed to choose the 'right' one. Other people felt quite strongly that there should be professional back-up (not just care/support planners or brokers) to help people make choices about their health care:

Some people might think oh yeah, we can manage it ourselves and we can do that, but I don't think you can because ... you haven't got the back-up, you haven't got the ... knowledge and what have you, have you, to sort it out yourself.

### 2.3 Overall impact of the personal health budget

Interviewees were asked whether they felt that the personal health budget had made a difference to their life or to how they felt about themselves. The majority of people felt that the personal health budget had had a positive impact on their lives. Some people felt that the budget had changed their lives by giving them hope for the future, greater motivation to improve their health, increased social participation and improved mental health and well-being: *'well if anyone asked me what it did for me I'd say it give me my life back, honest, it has changed me completely'*.

One person felt that the budget had had a detrimental impact on their quality of life because of the stress involved in having to ask for items, the refusal of their requests and the waiting times involved in third party management of their budget.

Just under a fifth of interviewees said that they did not think that the personal health budget had had any impact at all on their quality of life: sometimes this was because they perceived that there was not enough money in their budget for it to have any great impact.

Nevertheless, a majority of interviewees said that they would recommend the personal health budget to other people, in most cases wholeheartedly. Others in this group said that they would recommend it with provisos; that people were capable of making decisions, that people asked lots of questions about it and, finally, provided it was administered more efficiently.

### 2.4 Summary

On the whole, budget holders reported positive impacts from the personal health budget. However, this finding should be considered in the light of the problems some people experienced in the implementation of their personal health budget (see Section 6). That said, only a minority of people did not think that the personal health budget had actually had any positive impacts for them.

The main beneficial impacts as perceived by the budget holders themselves included (increased) choice and flexibility in their health care arrangements; improvements in their health and outlook on life; increased motivation and/or confidence; an improved social life; and better information about their condition.

The majority of budget holders across all condition groups in the sample also reported positive impacts on their health and well-being and it was not unusual for people to report improvements in all areas of their health and well-being (i.e. physical and mental health). In some cases these impacts of the personal health budget had been greater than people had expected.

Few people reported any great impact from the personal health budget on their use of health or other services or on their relationships with health professionals; in some

cases this was because there had not been any other services or health care in place.

It was also common for people to report positive indirect impacts of the personal health budget on their family and friends; other family members were less worried about the budget holder and in some cases also had more free time, where they had previously been providing care for the budget holder.

On the whole, people felt that their personal health budget had increased the amount of choice and control they had over their health care; and had increased their choice of services and items and funds to purchase them. Greater flexibility was experienced by some people through being able to choose providers of services and to arrange services at times to suit themselves.

Other people reported that they felt their choices had been constrained by panel decisions, the lack of services in their area, the lack of control over their budget (where budgets were managed by a third party), and the low level of their budget.

The majority of people were comfortable in making choices about their health care. Some others, however, had found making the 'right' choice difficult and a few people felt strongly that there should be professional advice available for people [on which to draw] when making decisions about their health and health care. Some people needed substantial information, advice and support to inform their decision-making and choose services, but this was not always available for them.

### 3. How Personal Health Budgets Were Used

When budget holders were interviewed three months after being offered a personal health budget (Irvine *et al.*, 2011), it was more common for them to be using (or planning to use) the budget to buy new, additional services or items, or to fund items they were previously purchasing privately (because they were unavailable through the NHS), than to pay for alternatives to existing NHS care<sup>1</sup>. The main exception was where budget holders were able to switch from a previous care provider and employ their own paid carers/personal assistants instead.

Some pilot sites had provided prospective budget holders with lists of potential uses for personal health budgets. Most interviewees had, at the three-month interview, decided to spend their budget on items included on these lists. Those from sites without such lists had been encouraged to think ‘outside the box’ but would have welcomed ideas, suggestions or examples of permissible uses. The most commonly mentioned (planned) uses of personal health budgets in the three-month interviews were for paid carers/personal assistants, physical exercise and alternative or complementary therapies.

The remainder of this section describes how personal health budgets were actually used, including any changes in use, desired uses that were not approved, and reflections on choices made.

#### 3.1 Uses of personal health budgets

Table 3.1 lists the items that interviewees had purchased with their personal health budgets. The most commonly mentioned types of uses were the same as those planned at the three-month interviews; these were paid carers/personal assistants, physical exercise and alternative or complementary therapies. However, some minor changes had been made to how services or treatments were organised, for example people rearranged their care into longer blocks of time rather than many short visits.

**Table 3.1 Uses of personal health budgets at 9 months**

<b><i>Type of use</i></b>	<b><i>Examples</i></b>
Care	Employing carers or personal assistants, respite care
Physical health care treatments	Physiotherapy, neuro-physiotherapy, speech therapy, occupational therapy
Health care or personal care equipment	Nebuliser, sanitary equipment, aprons and rubber gloves

<sup>1</sup> This may reflect different practices in the pilot PCTs. Some were funding personal health budgets by substituting these for some of the funding and services previously received by individual patients; other PCTs were funding personal health budgets from additional resources.

<b>Type of use</b>	<b>Examples</b>
Psychological therapies and counselling	Neuro-linguistic sessions, counselling
Alternative or complementary therapies	Acupuncture, Reiki, massage, reflexology, yoga, Chinese medicine, bio-neuro therapy
Cosmetic/beauty treatments	Manicure, hair removal, hairdresser
Physical exercise	Gym membership, exercise classes, home exercise equipment, personal training
Improved dietary management	Frozen meals delivered, dietetics sessions
Computers/technology	Laptop, mobile phone, satellite navigation device, emergency 999 telecare system
Aids and adaptations	Wheelchair, adjustable armchair, adjustable table
Facilitating social activities and hobbies	Season ticket, craft materials, musical instrument, driving lessons, childcare, clothes, activity day with friends, theatre trip
Domestic help	Gardener, cleaner
Domestic appliances	Fridge, freezer, blender
Travel/transport	Travel to/from gym, travel for husband to make hospital visits, mobility scooter
Administration fees	Providers of employment administrative support (taxation, National Insurance), staff training

Physical health care treatments such as physiotherapy, speech therapy and occupational therapy were used primarily by those interviewees who had had a stroke. Two sites that piloted personal health budgets for stroke were involved in this qualitative element of the evaluation. In one of these sites, personal health budgets were offered a number of years after the stroke. In the other, budgets were offered immediately following the stroke and were used for routine NHS stroke rehabilitation treatments. Budget holders in the latter site were not usually aware that their budget was being used for routine care until a few weeks after discharge from hospital and, in many cases, would have preferred it not to have been used this way. None of the budget holders from other sites in this sample reported using their budgets for standard NHS care.

### 3.2 Differences between actual and planned uses

The majority of personal health budget holders interviewed after nine months had used their budgets in the ways they had planned at three months. However, some planned uses were either never taken up or not pursued. This was usually because people did not feel the need for them; or had tried them but found them less useful than expected (typically complementary therapies such as Tai Chi or yoga classes); or because they felt they had been cajoled into agreeing to them by the personal

health budget lead officer (examples included reflexology or swimming sessions). Some people changed their planned uses because they felt approval and implementation of their budget plans took too long. For example, one woman had hoped to use part of her budget to buy a second house telephone that could be kept upstairs so she could reduce the risk of falling down the stairs when rushing to answer the phone; by the time approval was granted she was more mobile and receiving fewer important medical calls so no longer needed the additional telephone.

Occasionally, budget holders reported that their budgets were being used to pay for things they did not remember asking for or did not think they needed; they therefore stopped these services. This was often the case in the site that used personal health budgets to pay for routine NHS stroke rehabilitation services such as speech therapy and physiotherapy. When people opted to stop receiving services, they either stopped them themselves or asked the personal health budget lead officer to do so - a panel was not involved.

People rarely had to change their planned uses because the budget was insufficient. On just two occasions, people found themselves having to choose between options after they had been approved, because of inadequate funds in the budget.

It is notable that a significant minority of people remained confused about what their personal health budget was being used for. A particular confusion was about which items were paid for from the personal health budget and which from other NHS funds. This was especially confusing for those people who had been told that their personal health budgets were to cover all aspects of stroke recovery, but who found that the cost of some treatments was not taken from the budget. Others remained confused because they were reluctant to ask the personal health budget teams too many questions for fear of being a '*bother*'. A major area of uncertainty was whether or not there were any funds left in their personal health budget and therefore whether additional uses could be planned.

### 3.3 Experiences of requests being turned down

Uses of personal health budgets usually had to be approved by a panel. Personal health budget leads submitted requests to a panel on behalf of the budget holder. Around a fifth of budget holders in this sample reported that they had had preferred uses turned down. Some of these requests were turned down by the personal health budget panels; others were not taken to a panel because the personal health budget lead officer felt the requests were not appropriate. In addition to requests being turned down through these official channels, many people decided not to ask for certain items. This was either because they felt uncomfortable asking for (rather than being offered) items or because they had had earlier requests turned down and so felt reluctant to make new requests, even though these might be for quite different things.

There were differences between pilot sites in the types of items and services approved. Personal health budget holders in some sites reported that items such as laptops had been approved, but in others similar items were deemed to be insufficiently health-related or did not fit the local personal health budget criteria. One



example of a refusal was the purchase of a laptop by a woman who was confined to bed; she had hoped to use the laptop to undertake online courses, to manage her medication and to help with socialising. The request was turned down as it was deemed not sufficiently health-related. Another example was a man who had been awarded a personal health budget to help with mental health problems; he was told that he could not use his budget to pay a support worker to help him with shopping as this was related to physical not mental health. He subsequently asked if he could use the budget to pay for delivery charges for internet shopping instead, but was refused for the same reason. There were also inconsistencies between sites in whether personal health budgets could be used to fund carers or companions to accompany budget holders on approved activities. For example, another man with mental health problems felt uncomfortable going out on his own. He was allowed to use his budget to pay for him and some friends to go on an outdoor activity day. However, after the event he was told that this was a mistake and that in future he would only be allowed to use the budget to pay for himself, not others. In contrast, another site had allowed a woman to pay for a theatre trip which included paying for her mother to accompany her. Refusals were made by personal health budget panels as well as through more informal discussions with personal health budget leads.

Another common reason for particular uses of the budget being disallowed was that there were alternative sources of funding available, such as prescriptions or referrals via GPs, or other budgets such as aids and adaptations. For example, one woman reported that she had been told she must try to purchase various pieces of equipment (such as a shower sling and adjustable bed) from the aids and adaptation budget and only if this failed could she apply to use her personal health budget. Discussions such as these appeared to take place between the budget holder and the personal health budget lead; as a result, these requests were never made formally to a panel.

Risk to the budget holder was rarely mentioned as a reason for requests being refused. Exceptions included two men who had had strokes and were refused permission to spend their budget on certain types of exercise because of balance problems; one wanted to go swimming and the other to buy a rowing machine. These refusals were made by physiotherapists. One of these men was also refused, but on a temporary basis, permission to buy fishing equipment; he was advised by the personal health budget lead officer to borrow equipment to see if he could cope with using it and, if he could, his request would be submitted to a panel.

People who had requests turned down felt disappointed and frustrated. This was particularly the case if they felt they had valid cases for purchasing the items. Some budget holders had used the internet to see what items other people in the pilot sites had purchased and felt especially aggrieved that they had been refused items that other people, with what they felt were similar or less intensive needs, had been allowed to use their budget for. One woman who had had a stroke reported numerous purchases being refused by a panel because she had not sought permission before buying the items; these included various pieces of home exercise equipment and some chiropractic shoes. She had not sought permission because she had experienced long delays with (and ultimately cancellation of) an earlier

purchase of equipment via the official channels; time was very important to her in her early days of stroke recovery. Multiple refusals resulted in people no longer asking for items to be funded from their personal health budget; some bought them with their own money instead. Occasionally people felt that they had run out of ideas and struggled to think of alternatives that they really wanted to spend the budget on (at the extreme, one woman had had 11 requests refused).

### 3.4 Future plans for personal health budget use

There was a great deal of uncertainty among interviewees about whether or not budgets would be continuing for another year (see section 6.6) and only one person reported concrete plans for the on-going use of his personal health budget. Where people did have ideas for future use, these included continuing with current uses or, in a few cases, trying again to gain permission to use their budgets in ways that had previously been refused. There were few planned changes in use. Some people who were already buying items with their own money hoped to use their budget instead; others had no plans as yet but hoped someone would help them generate some ideas. There was still confusion about what constituted valid uses: *'I'd have to find out what the personal health budget really is for, to be honest [laughs] and then I could look at things maybe [laughs].'*

### 3.5 Overall reflections on use

Around three-quarters of the people in this sample who had a personal health budget in place felt that the way it had been used was right for them. A minority felt that their personal health budget could have been used in better ways. The main reasons for these views were that there had been no benefit from the services or treatments purchased with the budget; the outcomes had been disappointing compared to expectations; and that the services that were allowed to be purchased from the budget were not those that were wanted.

Where people expressed a view, services or items that would have been preferred to a personal health budget included treatments such as full body scans (to give reassurance about diseases) and organ transplants. Some people felt unable to express a view as they did not know what alternatives existed; others expressed a preference for items such as group exercise classes or gym membership. Together, these suggest a lack of understanding about how personal health budgets could be used, though this was not universal. There was also some confusion about how personal health budgets were funded, as some people said they would have preferred to have their services funded by the NHS or felt that pooling the money to pay for more NHS services might be a better use.

### 3.6 Summary

The majority of budget holders had used their budgets in the ways they had planned when interviewed at three months. The most common types of uses were for: paid carers/personal assistants; physical exercise; and complementary or alternative therapies. Changes in use usually resulted from people deciding they did not need a piece of equipment or service, or from initial outcomes being poorer than expected.

A significant minority of people remained confused about what their personal health budget was being used for and/or the amount of funds left in the budget for other uses.

There were discrepancies between the pilot sites in the types of items and services that were approved for use of a personal health budget. Some items or services that were apparently deemed sufficiently health-related in some sites were not approved in others. People who had requests turned down felt disappointed and frustrated, particularly where they knew that people in other pilot sites had had similar requests approved.

In general, people felt the way they had used their personal health budgets was the right way for them.

## 4. Level of the Personal Health Budget

This section of the report considers whether interviewees felt the level of their personal health budget was sufficient to meet their needs.

As the fourth interim report (Irvine *et al.*, 2011) showed, at the time of the three-month interviews many of the study participants were unaware of the actual amount of their personal health budget. Some of those who did know the amount of their budget at three months, whilst mostly satisfied with the amount, did not actually understand how their budgets had been worked out.

By the time of their nine-month interview, most people knew the amount of their personal health budget. Of those who did not, in one or two cases this appeared to be related to the perception that the personal health budget was actually a 'pot' of money held centrally rather than an individual allocation of funding.

In the nine-month interviews, budget holders were asked whether the amount of their budget had changed; whether the budget had been enough to meet their needs; and whether they had used their own money to purchase anything related to their health care which was in some way linked to their personal health budget.

### 4.1 People who perceived the level of the personal health budget fitted with their needs

Just under half of the sample thought that the level of their personal health budget was adequate for their needs. Analysis shows a number of reasons for this. Some people seemed satisfied with the amount they had been given primarily because there was still some money left in their personal health budget: *'must be about right cos I've still got some left'*. Others appeared satisfied because the level of the budget had allowed them to access the services or items they felt they needed. For example, people said that they had been able to get the number of sessions of alternative therapies or counselling sessions they had wanted, or that the money had been enough to buy a particular item like a laptop, a fridge, or a piano. *'I'm quite happy [ ] I used it on acupuncture [ ] it's helped me improve'*.

A minority of people said that they were satisfied with the level of their budget but that they were struggling to think what they might use their budget for; in some of these cases their suggested items had been refused by a panel:

If it were cash, phew, I wouldn't be complaining [ ] I'd be spending it straight away. But you've got to buy, spend it on stuff that they [ ] want you to spend it on.

One of these people had not long realised that he had £500 per quarter to spend; at the time of his three-month interview he had thought that his budget was £500 per year. The budget holder perceived that the personal health budget lead had not made this clear and he had subsequently lost out on quite a lot of potential goods and services that he could have used the budget for.

People who did not know how much their budget actually was could also be unsure whether their budget would be enough for their needs: *'I think it is [ ] the problem is we don't know how much we've spent'*. Whilst not unhappy with the amount of their budget, one person said that they did not know how it had been worked out and so were unable to comment on whether it was enough for their needs. This person also said that they had been given the opportunity to ask for more money but had refused the offer. Other interviewees thought that whilst the budget was enough for their current needs, it would not be enough for future needs and the data showed that people appreciated their budget changing in response to their altered circumstances, where they need more care after an operation, for example.

## 4.2 People who were unsure whether the personal health budget met their needs

A large minority of the study sample said that they did not (yet) know whether the personal health budget was adequate to meet their needs. For example, one budget holder was only employing one carer at the time of the nine-month interview and felt that their budget was adequate at that time. However they were soon to employ a second carer and were unsure whether the budget would cover all of the related costs:

I have got a little bit in the bank and it's because I'm not having to pay that second carer [ ]. When I do get my second one and we've got settled, we've got a routine and things like that [ ] then I'll know whether [ ] it's enough or not.

This interviewee had recently had their budget increased after a review in which they told the personal health budget lead that they found it difficult to manage some weeks with the hours of care they had.

Some people felt unsure whether their budget was enough for their needs because they did not know how much was actually (left) in their personal health budget or, similarly, because they did not know how much money had actually been allocated to them.

Others in this group felt that they were unable to say whether the budget was enough to meet their needs because they had nothing to judge it by or because they did not know whether it would continue to cover their agreed needs: *'I'm worried that there's not going to be enough come the end of the year'*.

## 4.3 People who thought the level of the personal health budget was insufficient for their needs

Just over a fifth of the sample perceived that the amount of their personal health budget was not enough to meet their needs. This did not necessarily mean they were unhappy with the level of their budget. For example, one of these people said that they were happy to be getting some help with payments for their health care but that the budget did not cover all of the costs of the massage sessions they needed or the costs of advertising for carers or all of their care needs. This person also recalled being told that the amount of the budget might change in the future.

Similarly, some of the people in this group said at their nine-month interview that although the personal health budget had been '*life changing*' for them, it nevertheless did not cover all of their associated costs: '*there are some things that I just haven't been able to afford to do, which is unfortunate*'. For example, one interviewee was meeting some of the travel costs involved in using the gym; another budget holder had to '*juggle*' their budget to cover bits and pieces of the services they had initially asked for in their care support plan.

Other people in this group said that they would ideally like to have more hours of care; cleaning; physiotherapy and alternative therapy sessions.

Two people were more strongly dissatisfied with the level of their personal health budget, because it had not met their needs.

#### 4.4 Private expenditure related to the personal health budget

Across all of the groups above, some people had used their own money to pay for health or well-being related items or services. The main reasons for this include a lack of information and understanding about what the personal health budget was and how it could be spent; not having enough funds in the budget and having requests for desired items/services turned down. These are covered in more detail below.

##### 4.4.1 Insufficient understanding and information

There was a general lack of understanding about the permitted uses of the personal health budget amongst some interviewees. Primarily these people also thought the budget was not enough to meet their needs or were unsure whether the budget would meet their needs. In some cases, it had simply not occurred to interviewees to use the personal health budget to pay for items or they had not perceived that they would be allowed to do so. This was the case for people who had bought a piano stand (the piano was bought with the budget) and an electronic cigarette, for example.

Similarly, some people who were not clear that the budget was a personalised funding allocation had purchased items themselves. For example, one person had thought that their item was more a '*want*' than a need and that it would be unfair to ask to fund it from the personal health budget when other people had needs that could be met with the money:

I'm a bit scared really, cos somebody else who [ ] could be in a position where they need summat and I'm taking money away from it and it could put them at a loss. So I'm a little bit wary of asking for things.

Another interviewee who thought that the personal health budget was a shared '*pot*' of money said that they paid for anything under £100 themselves because they were not '*people for begging*'.

One other person recounted how they had ended up spending their own money on an item related to the personal health budget because they were unclear as to whether the budget would fund the cost and had been unable to contact anyone to

ask. The cost in question was directly related to the use of their budget; the budget was paying for driving lessons but the participant did not have a provisional licence and ended up paying for this themselves. In doing so, however, they had become overdrawn at the bank.

#### 4.4.2 Costs refused

Another reason that people had paid for items and services themselves was because their requests had previously been refused by the personal health budget lead officer or panel (see section 3.3). Examples here included wheelchair servicing costs, vitamins and supplements, alternative therapies and costs associated with employing carers (e.g. additional rent and heating bills). One interviewee who was not happy about having to pay for fuel costs to transport the budget holder had been told that the budget would not cover these costs because they had a vehicle through the Motability scheme. Some people reported that they were not always given a full explanation as to why particular costs had been refused.

One interviewee reported that he was paying towards his specialised physiotherapy after his budget had been calculated on the basis of an average of four quotations he had obtained from different practitioners. The practitioner he had chosen to go to, however, had specialised expertise for his condition, but cost more than this average:

They said, well no, we're not going to give you the full amount, we can give you a basic rate and then [ ] you're going to have to pay the, pay a top up for that.

#### 4.4.3 Insufficient funds in the personal health budget

Finally, some people reported that their budget did not cover the costs of all of the services they used. This could be the case where interviewees thought they had been awarded a 'set' or 'standard' amount of money. An example of this was someone who was awarded £500 and was using it to fund some, but not all, of his use of alternative therapies. Another person reported that he funded some of his own trips to the gym in addition to those that were funded by the personal health budget.

Those who were paying for goods and services themselves because the costs had been refused or because there was insufficient funds in their budget to cover them, were also likely to think that the personal health budget was not enough to meet their needs.

### 4.5 Summary

At the time of their nine-month interview most people knew the level of their personal health budget. Some people, however, still lacked this information. Those people who thought the personal health budget came from a shared 'pot' of money were amongst those who did not know the amount that had been allocated to them.

Just under half of the sample group thought that the amount of their budget was adequate for their needs. However, some of these interviewees had had plans for spending their budget refused by a panel and said that they could think of nothing

else to spend their budget on. A large minority of people were still unsure whether their personal health budget would be enough to cover their needs, while a fifth of the sample perceived that the amount of their personal health budget did not meet their needs. Some of the latter group were not necessarily unhappy with the level of their budget (although some clearly were).

For a variety of reasons, people in all these groups had used private funds to purchase items and services which were related to their personal health budget. Instances included paying for goods and services because people did not think to ask whether the budget could fund the items in question; paying for items which had been refused by personal health budget staff or panels or delayed because of the implementation of the personal health budget; and adding private funds to their budget to pay for additional or more expensive services. In some cases the implication of this was financial hardship for people.





## 5. Managing the Personal Health Budget

This section of the report details the arrangements that budget holders had in place for managing their personal health budgets, and their experiences of these, at the time of their nine-month interviews.

As the fourth interim report (Irvine *et al.*, 2011) highlighted, not all of the study participants had made arrangements for managing their personal health budgets at the three-month stage. By the time of the nine-month interviews, most people had management arrangements in place. However, there were some budget holders who did not know how their budgets were actually being managed (which in effect suggests that they may have had PCT or third party management). One of these people reported that they would ideally have liked to manage the budget themselves.

Known deployment options at nine-months consisted of PCT or third party management and direct payments, which are discussed in turn, below.

### 5.1 PCT or third party management

Just over half of those who had their personal health budgets in place at nine months had PCT or third party management of their budgets.

#### 5.1.1 Advantages of PCT or third party management

The majority of these budget holders reported no management problems and some people cited positive aspects of having their budget managed by the PCT or a third party, which echo those outlined by respondents at three months. These included not being able to spend the money inappropriately if it was held by someone else; not having to deal with the stress of managing the money oneself; and the PCT or third party being in a better bargaining position to get good deals. One of these people, who thought the personal health budget came from a collective 'pot', thought that other people could potentially spend what they did not need or use, rather than the money *'languishing in my drawer somewhere'*.

At the same time, some people were more ambivalent about PCT or third party management. One person thought that the implication of having their budget managed for them was that they were considered unable to look after it themselves: *'they don't think you can look after yourself [ ] "so [ ] we'll look after it for you"*. Another interviewee said that they needed to remember to ask for approval before paying for something (in cases where they were permitted to claim expenses back). A third interviewee thought that whilst the personal health budget might have been too onerous for her to manage herself, she would have liked more information earlier on in the planning process about what the money was being spent on, how much things cost, and who actually decided on its use.

#### 5.1.2 Disadvantages of PCT or third party management

For some people, PCT or third party management of their budget had not worked out very well. However, one interviewee said that they would be reluctant to take a direct

payment instead because, when it had been explained, it had sounded risky in that any costs later deemed unsuitable at a personal health budget review would have to be reimbursed.

Delays, in a few cases of some months, in waiting for goods or services procured via the PCT or third party management were experienced by some people. Consequently some said that, on reflection, they would have preferred a direct payment. One person said they would have liked more control over the money than was allocated to them and another person thought that having to request money for an item was *'a bit like having to [ ] ask your mum for pocket money'*.

One person, who would have preferred a direct payment, reported feeling very embarrassed when her gym fees were repeatedly unpaid. This caused the budget holder stress and put her off going to the gym as much as she would otherwise have done.

Finally, one budget holder had concerns that her money was being wasted because gym sessions were paid for on a weekly basis regardless of whether or not she attended the classes. The budget also paid for crèche sessions but the crèche had closed down. With hindsight, the budget holder would have preferred more control over the money in order to avoid this waste.

## 5.2 Direct payments

### 5.2.1 Advantages of direct payments

There was an overall consensus amongst those people who had a direct payment that this had been the right option for them. That said, nearly half of this group said that they had had some (mostly initial teething) problems with this deployment option. These included problems with getting bank accounts set up and running; managing accounts and paying for goods online; money being paid late into budget holders' accounts; and not being notified when money had been deposited into accounts.

The majority of people using direct payments were employing their own carer or PA. Their experiences of recruiting staff and managing the associated employee administration are discussed below.

### 5.2.2 Help with recruiting staff

A number of those who had employed staff through their personal health budget had not needed much help with recruiting. In some cases, this was because people had staff already in place from their previous social care package and so had not needed to recruit. In another case, the budget holder was getting staff from a care agency and so was not, in effect, directly employing anyone. Mostly this sub-group had not recruited carers or PAs through the open labour market, instead employing relatives, friends or acquaintances:

I don't advertise and recruit staff, I just get people through word of mouth, friends of friends and things, that sort of thing.

Some people had employed staff with the help of the personal health budget lead officer and other professionals. One person explained how her support worker had been very helpful in this respect; her support worker had placed the recruitment advertisement, after checking requirements with the budget holder, and had forwarded application forms to the budget holder for inspection. The budget holder had then chosen who she wanted to interview and the support worker had set up the interviews and helped to carry them out on professional premises, rather than the budget holder's home. The budget holder had very much appreciated this level of involvement, saying it had been '*a weight off my shoulders*'. In another instance, the personal health budget lead officer had suggested someone they thought might be suitable for the budget holder to employ when the budget holder had sacked their previous carer.

There were a few people in this group who reported some difficulties in recruiting staff. These difficulties related to finding suitable staff in their geographical area: '*it was just the calibre of staff coming through the door [ ] Really, really hard*'; covering the costs of advertising for staff; and finding potential applicants who were willing to work on a payroll and not 'cash in hand'.

### **5.2.3 Experiences of Criminal Records Bureau checks**

Some budget holders had not thought it necessary to get Criminal Records Bureau checks carried out on (potential) employees. This was the case when they were employing relatives or employing staff who already had Criminal Records Bureau checks in place. One budget holder had arranged Criminal Records Bureau checks through his support worker and had found this very helpful.

### **5.2.4 Managing employment arrangements**

Of those budget holders who were employing staff, there was just about an equal split between those who had decided to manage the employment arrangements, like tax and National Insurance, themselves; and those who were using an agency to help them or to do so on their behalf.

Of those who had decided to manage these arrangements themselves, some felt initially daunted and found it helpful to have back-up (e.g. from social care professionals) that could be called on if needed. Other people had help with managing employment arrangements from friends and family. Some people found it very difficult to draw up employment contracts for staff and had ended up modifying examples they had found on the internet.

There were one or two examples of budget holders who subsequently had not been happy with the person they had employed. One of these did not feel able to dismiss the employee because they did not feel confident enough to confront them. The budget holder's support worker had been extremely helpful in this situation, outlining the procedures to be followed and eventually dismissing the carer on the budget holder's behalf: '*I wouldn't be able to do it, I know that for a fact [ ] so she says "look if you want me to do it, then I'll do it"*'. This emphasises the importance of having such back-up support for managing employment relations for budget holders.

### 5.3 Summary

Most of the study sample had management options in place by the time of their nine-month interviews. Some people still lacked information on this aspect of their budget, however, even though their budget was up and running. There were also reports of a more general lack of detailed information available prior to choosing a management option.

An advantage of PCT or third party management of the personal health budget was reported to be the peace of mind in not having to manage the money oneself. Disadvantages included delays in administration and in the receipt of ordered goods and services, failure to pay fees promptly, and (perceived) inefficiencies in paying for unused services. Some people with third party management would, given these problems, prefer to have a direct payment.

People who had direct payments were on the whole happy with this option, even though some had encountered teething problems in setting up accounts.

The experiences of those budget holders who were employing staff with their personal health budget highlight the importance of receiving information and support with recruitment of staff, help with the administration associated with employing staff, and assistance if things go wrong.

## 6. Implementing Personal Health Budgets

This section describes people's experiences of implementing personal health budgets. It includes reflections on the usefulness of help and information with initial care/support planning; interviewees' experiences of approval processes and of getting their desired service options in place; experiences of reviews; implementing personal health budgets alongside personal budgets for social care; and knowledge about the future of personal health budgets.

Despite these interviews being undertaken around nine months after being offered a personal health budget, there was still a considerable degree of uncertainty for many people about whether or not they had a personal health budget, what it could be used for, or what it was being used for. This is illustrated by a man who was very pleased with the people he had met over the previous few months but had no idea whether they had anything to do with personal health budgets:

I think where we've fallen down is that nobody has actually mentioned the word 'health budget' when visiting. ... So you don't know actually whether they're actually talking about this health budget or whether, you know, it's [the reason they are visiting] just something that's cropped up and they want to talk to you.

People who already had condition-specific recovery plans, for example for stroke or mental health problems, found it difficult to differentiate between these plans and their personal health budget care/support plan.

### 6.1 Reflections on information and advice with initial care/support planning

Budget holders expressed mixed views when asked to reflect back on the information and advice they had received during the initial care/support planning. Many people were satisfied with the help and advice they had received in planning how to use their personal health budget and could not praise their contacts enough. Some needed no help at all as they already knew what they wanted to use the budget for; others felt that it took them some time to get used to being involved in their care/support planning, but once they did it was an '*excellent*' experience. An important reason for this was that they felt that '*somebody cared*'.

People found it especially helpful to be given information about the range of options available to them and how other people in similar circumstances had spent their budget. Where this type of information was not provided, people found it hard to know where to start in thinking about how to use the budget. More condition-specific examples of how people had used budgets and how it had helped improve their lives would have been particularly appreciated. Some people, however, found a list or 'menu' of options restrictive as they felt uncomfortable in making requests for items not on such lists.

It is notable that those interviewees who were offered a personal health budget very shortly after a stroke (for many this was within days of quite severe strokes and whilst still in hospital) felt that they were offered it too soon and were not in a position

to plan their support needs: *'when you're not well, and I was still quite confused early on, it's hard to really know what you're gonna need and what you want ...'*. In the first few days after the stroke they felt, with hindsight, *'still slightly shell-shocked'* and not able to understand fully what a personal health budget was about. Spouses or other family members were also unable to take in information about personal health budgets because they too were overwhelmed by events. A common view from these budget holders was that the initial stages of stroke recovery should follow standard NHS procedures; the option to receive a personal health budget should only be given after this initial recovery process. In the site that offered personal health budgets a number of years after a stroke, budget holders held more positive views.

Some people did not feel that they had been given a chance to be involved in their care/support planning; they typically felt that *'they were [in charge] [laughs], whoever they are!'*. This lack of involvement could be disappointing and lead people to question whether they had been expecting too much. Others had no recollection of any care/support planning process:

I didn't actually see anybody that worked for the, whoever gives the personal health budget out, I never saw anybody from any department anywhere. I don't even know whether it's a government fund or what. No idea.

The fact that personal health budgets were being piloted, and therefore the staff who were helping with care/support planning were new to the process, was felt to be a reason why some staff lacked information or were confused; this was not helped by multiple staff changes. Some budget holders had been frustrated with the lack of support they received but, with hindsight, understood that everyone was going through a learning process and, in some cases, felt that the help and information they received later in their experience was much improved. Others felt that the lack of support from personal health budget staff made it all the more important to have friends, family or independent advocates to act on their behalf during the care/support planning process.

Whilst people were generally grateful to receive a budget, some felt that information on how to use the personal health budget was not offered as freely as they would have liked. Although this was not perceived as a problem by people who were happy to ask questions, others felt uncomfortable doing so and in some cases this resulted in them spending very little of their budget. There were also instances where people felt pressured by personal health budget officers into using the budget for services that the budget holder was unsure about. Occasionally people discovered they were using their budgets for things they did not remember agreeing to. Lack of information on why budgets had been set at certain levels and about who owned the items purchased (and consequently whether items would need to be handed back at the end of the pilot) also caused concern and frustration. People felt that having a mix of clear written and verbal information about personal health budgets and how they could be used would have helped to ease anxiety and uncertainty.

## 6.2 Experiences of approval processes

Experiences of getting approval to spend their personal health budgets on items identified in their plans varied from what were perceived to be quick and smooth processes to ones that were more complex and lengthy. Gaining approval usually involved the personal health budget lead officer submitting a care/support plan to a board or panel. Budget holders did not know who sat on these panels. Some people felt as if their contact acted as an advocate and fought their case for them; others thought their contact had little say in the process and merely submitted a request.

Many care/support plans were approved with no delays; this usually meant approval was granted within a couple of weeks of the application being submitted to the PCT panel. People who were given personal health budgets for stroke recovery in one site were automatically given immediate approval to use their budgets for mainstream NHS services such as speech therapy and physiotherapy. There were also occasions in other sites where people were given approval immediately by their personal health budget lead officer; in one case this was understood by the budget holder to be in lieu of panel approval but in others it was seen as unofficial approval aimed at reducing uncertainty for budget holders while they waited for official panel approval.

Many people reported significant delays in gaining approval ranging from a few weeks to eight or nine months. The reasons for these delays were often not known but assumed to be *'red tape'* and *'bureaucracy'*. Common reasons for delays, where these were known, included risk assessments from GPs and hospital doctors (typically these involved gaining agreements for people to join gyms or use home exercise equipment); and the fact that some items requested were not on approved lists and there was no precedent set by the item having been approved for anyone else.

Some people felt that a delay of a few weeks in gaining approval was not a problem for them; for others it could cause quite major distress. The reason for this may be related in part to the person's underlying condition. For example, people who had relatively stable conditions appeared to be less distressed and frustrated by delays in approval than people who were using their personal health budgets to aid recovery from a recent health event (such as a stroke or mental health relapse). Where people did feel frustrated by delays, they used words such as *'saddened'*, *'upset'*, *'uncertain'* and *'destabilised'* to describe their emotions.

Delays in approval impacted on people in different ways. Sometimes the delays meant that, by the time approval was given, the item was no longer needed. People felt particularly aggrieved if they had waited a long time for approval and were then told they had to make their purchase and submit the receipt very quickly. Some people felt very annoyed that delays in gaining approval meant that spur-of-the-moment purchases could not be made. Such purchases included buying second-hand items (often home exercise equipment from charity shops) that were a fraction of the price of new ones. People also felt that valuable time was wasted if they knew that they wanted to start a particular treatment or exercise but had to wait several weeks before gaining approval to do so. One solution that was suggested was to book treatment/exercise sessions a few weeks in advance to give time for approval



to be given, rather than waiting for approval and then waiting again until a treatment slot became available.

### 6.3 Experiences of getting approved options in place

Once approval had been given to purchase items or treatments, the process of sourcing and arranging delivery began. People's experiences of this varied from a smooth process with no delays, to stressful processes with lengthy delays. People who had experienced no delay usually had few comments on the process; they were content with it and not concerned with why it had worked well. However, there was a belief that items or treatments that were listed on an approved personal health budgets 'menu' could be arranged quite quickly; in one case this involved the budget holder taking his letter of approval to his first appointment with an acupuncturist who then contacted the personal health budget team and arranged the payment himself. A few people actually chose to delay implementation of their budget because they were not ready to receive certain items or treatments, or could not decide on the supplier (for example, which gym to attend).

For other people the process was not as smooth. An important reason given for delays in implementation was the perception that administration and communication on the part of the personal health budget team was poor. Budget holders felt that the personal health budget teams did not communicate with them often enough to keep them informed of progress; there could be weeks and sometimes months between contacts. While some people were happy to keep chasing, others found this frustrating or did not feel it was appropriate for them to '*pester*' the personal health budget team. Budget holders thought that typical reasons for delays were staff changes and leave; emails and phone calls could be left unanswered until staff returned from holiday. Equally frustrating was the length of time taken in some cases to source appropriate items; this was particularly annoying for people who knew exactly what item they wanted (for example a mobile phone or piece of exercise equipment) and who could have purchased it from a local shop, but had to wait for the personal health budget team to source it from elsewhere. In a minority of cases there was a multistage approval and implementation process with, for example, gym membership being approved by a panel, followed by the budget holder sourcing an appropriate gym, and finally the details of the chosen gym being taken back to a panel for approval.

Problems with supply were also an important factor in delayed implementation. Occasionally, items were out of stock or delivered in damaged condition; this caused delays in waiting for stock or a replacement item, or in sourcing a new supplier. The reasons for delays were often not communicated immediately to the budget holder. In a few cases additional risk assessments were necessary. For example, although a panel had approved use of the budget for driving lessons, the DVLA undertook its own risk assessment of one budget holder. At the time of the three-month interviews, a number of people with diabetes had requested the delivery of boxes of fruit and vegetables to help improve their diet. These requests turned out to be problematic as the supplier could only deliver at certain times on certain days, would not leave the box with neighbours and would only deliver in certain areas; this meant that people who worked or who lived off the standard route could not receive the boxes.

Delays in implementation could make people feel anxious, angry and annoyed. The consequences of delays included people paying for items themselves, resulting in them being out of pocket, either temporarily or permanently. Of the people who had to pay for items or treatments upfront and then claim the costs back, some found this acceptable as they had sufficient savings, but they worried about those who were less well off. Payment upfront was typically a result of problems in opening special bank accounts for the personal health budget to be deposited in, but sometimes also arose because people wanted to get on and begin their approved treatments as soon as possible without waiting for the personal health budget team to set up payment systems. In one extreme case, a woman had to pay out and claim back £8,500 to employ carers for four months. It seemed that reimbursements were (usually) made for items that had been approved or were on standard 'menus' of items, but not necessarily for items still in the process of being approved. This varied between sites. One woman began sessions of an alternative therapy once she knew the vouchers for this had been sent to her; however, an administrative error resulted in a delay in her receiving them so she paid for a session herself but was refused reimbursement. Others made spur-of-the-moment purchases of second hand items to try and save money; some were reimbursed but others not.

For some, delays in implementation resulted in them taking risks. One keen cyclist who wanted to buy a Wii exercise bike to help build up her strength and movement after a stroke, became so frustrated with the delays in getting the bike that she went out cycling by herself. She fell off the bike and hurt herself. An older woman, who waited a number of months for a chair with a raising seat and foot rest, began to put her feet up on a small table to alleviate the pain and swelling; she and her daughter knew this was a trip hazard but felt they had no choice.

Delays also impacted on other family members and on budget holders' lifestyles. Delays in organising paid carers/personal assistants (or in setting up bank accounts to enable budget holders to make these arrangements) meant that family members had to fill the care gaps or that budget holders had to continue receiving care from agencies or care workers they were not satisfied with. In many of these cases, the reason for wanting a personal health budget was to have more control over carers, so it was particularly disappointing to be subjected to such delays.

Some people were under the impression that personal health budgets were being piloted for 12 months, so the longer it took to receive an item or treatment, the shorter the amount of time left to benefit from it. This view was not expressed very often but, where it was, it was a major cause of anxiety.

Overall, budget holders wanted to see a reduction in bureaucracy and quicker approval and implementation processes to stop people becoming demoralised. As one woman put it:

... back then I wasn't really thinking much about the budget at all really because nothing, it was like a standstill, I kept wanting the bike but I wasn't getting it, so why bother asking for anything because it wasn't getting done? So I've given up really.

## 6.4 Experiences of reviews

The reviews that budget holders received varied in formality and timing. This may have been in part due to the different lengths of time interviewees had had their personal health budget arrangements in place (see section 1.3.1). Many people found it difficult to differentiate between formal and informal reviews but assumed that reviews that included forms being completed and checks on finances were formal. However, whether or not reviews were formal was of little consequence to budget holders; what was more important to them was that someone had been in contact.

Reviews were variously undertaken face-to-face, by telephone or by post. Budget holders commonly felt that the main purpose of reviews was to check that budgets were being used appropriately and that there were no overspends. Some reviews were undertaken after a set period of time, such as every 12 weeks, whereas others took place after a course of treatment or sessions of therapy had been completed. Many reviews had been arranged for 11 or 12 months after people had started to use their budget and were perceived as a check on finances at the year end, especially if there had been little ongoing contact in the meantime.

Although reviews were usually undertaken by the personal health budget lead officer who had helped the budget holder set up and plan the use of their budget, this was not always the case. Where different people undertook reviews, this was perceived to be due to staff changes or to different roles within the personal health budget team. Budget holders who had contact with many people from multiple agencies ran the risk of becoming confused about which reviews related to the personal health budget or who they should talk to if they had queries. Where there had been regular and/or formal reviews, these were perceived to be light touch. People used the following phrases to describe them: *'just kind of catching up'*; *'just how are you getting on and all that'*; and *'it was all comfortable and relaxed'*. An advantage of having reviews, whether formal or informal, was that they motivated budget holders to continue using the services or equipment purchased with their budget, for example, using exercise equipment or attending the gym. This in turn helped people to maintain any health benefits. Reviews also provided opportunities to overcome minor problems or generate new ideas on how to spend the budget.

However, over a third of those interviewed who had a personal budget in place had not had any form of review. This typically left people feeling *'disappointed'*, *'abandoned'* and *'a bit adrift'*. The main reasons for these feelings stemmed from fears about overspending; curiosity about how much money was left in the budget; the desire to generate new ideas on how to use the budget; and because budget holders wanted to know that somebody was taking responsibility and knew what was going on. As one person who had had no contact said: *'it all seems a bit of a pickle'*. Frustrations were particularly high when reviews had been arranged and cancelled a number of times. Less commonly, people who had had no problems with their budget and its use were content to be left to their own devices, although they too would have liked some reassurance about their spending and the future of the budget.

Within sites, as well as across sites, there appeared to be variations in the frequency of reviews and levels of ongoing contact that personal health budget teams had with budget holders. The reasons for this are not clear: some budget holders felt they had a personality clash with their PCT contacts or had given the impression that they did not need the money; others thought they appeared able to cope and so had been left alone. With hindsight the latter had wanted more contact; some felt comfortable in initiating contact whereas others preferred to wait to be approached. Those who waited but were not approached risked missing opportunities to use their budget. Some people believed that the personal health budget teams were so busy that they were right to concentrate their efforts on people who needed most support. In contrast, others considered that the lack of ongoing support more generally was '*not satisfactory*'.

### 6.5 Implementing personal health budgets alongside social care personal budgets

Seven out of the 52 people interviewed reported that they had a social care personal budget as well as a personal health budget. Three of these were either not involved in managing their social care personal budget or had no information about it. Four people were involved in managing both budgets. Two reported receiving NHS Continuing Healthcare funding as well as social care funding and stated that they kept both budgets in a single account. As far as each was aware, the rules about how the money could be spent were the same so they treated the two funds as one budget. They had not experienced any problems. Two aimed to keep their health and social care personal budgets entirely separate. Confusion about how the two budgets interrelated, combined with a lack of ongoing contact with her personal health budget lead, led one woman, however, to use her social care budget to pay for the child care she needed to enable her to attend her personal health budget-funded gym sessions.

### 6.6 Knowledge of the future of personal health budgets

Few budget holders had a clear idea about whether they would continue to receive a personal health budget for a second year. Many thought their budget would continue but were uncertain for how long. Views on how long personal health budgets would last varied but included a rolling 12 week basis, one to three years and '*for a while*'. One person had been advised to spend her budget as soon as she could in case it was not extended. Only one man had committed any of his budget for the following year. These levels of uncertainty left people feeling worried about the future.

People with no knowledge at all about the future of personal health budgets were also anxious. The strongest effect of having no knowledge was that people were left feeling worried that their services might suddenly stop; they were also disappointed that they had been given such poor information. Conversely, however, the lack of information about the future led to other people assuming that their personal health budget and associated services would continue.

Some people thought that their personal health budget had already finished. These people had typically had little or no communication from their personal health budget

lead officer. This had led them to believe that once the approved number of sessions (for example, at a gym or with an alternative therapist) had been completed, the budget ended; they believed quite firmly that if it was to continue, someone would have been in touch with them. While some people felt '*let down*' by the lack of communication, others were not concerned about the budget appearing to have ended, as they were pleased with what they had received.

Regardless of knowledge about the future, many people wanted to continue having a personal health budget. Typically, they wanted to do so to maintain the health improvements they felt they had gained from using the personal health budget. People used words such as '*a big fear*', '*dread*' and '*terrible*' when describing how they felt about the possibility of their budgets being stopped and their health deteriorating to its pre-personal health budget state. A few people, however, wanted to continue using a personal health budget for less positive reasons, either to help others learn from their poor experience or because, although there had been no advantage to the budget, there had been no disadvantage either. Some were hoping that the teething problems would be over and they would be able to receive services quicker in a second year.

Just three people thought they would not continue with a personal health budget for a second year, if it was offered. These people were content with the budgets they had already received and either could not think of anything else they would want to purchase or felt that they could gain as much health benefit without a budget.

## 6.7 Summary

When reflecting back, many people were satisfied with the information and advice they had received during the initial care/support planning process. They found it particularly helpful to be given information about the range of items or services available to purchase with their personal health budget. A notable exception was people who were offered a personal health budget very shortly after a stroke; this group generally felt that they were not in a position to understand personal health budgets or be fully involved in planning their use so soon after a stroke.

People's experiences of gaining approval to use their budgets as planned varied; some were quick processes and others quite lengthy. Approvals were usually given by a panel, but these panels lacked transparency. Administration and communication from panels and the personal health budget teams more widely was a concern, especially for people who did not feel comfortable initiating regular contact with the team. This lack of clear information could lead people to make assumptions that were not necessarily accurate. Lack of information about the future of personal health budgets was also a major concern; people were particularly concerned that their budget might stop suddenly and that their health may deteriorate to their pre-personal health budget state.

Some people felt that delays in approval or implementation of a few weeks were unacceptable; others were comfortable waiting longer. Waiting for approval could be especially frustrating for people who felt time was of the essence in their recovery.

Delays also affected risk taking, resulted in negative emotions and had knock-on effects on families.

Budget holders were unclear whether reviews were formal or informal, but felt the main issue for them was that someone had been in contact about the personal health budget. An important benefit from regular contact with personal health budget teams was that budget holders felt motivated to continue attending gym or therapy sessions or doing home exercises and thus maintain health improvements.



## 7. The Experience of Carers of Personal Health Budget Holders

### 7.1 Introduction

It is not just patients themselves but also their carers who may be affected, in a variety of different ways, from personal health budgets. A study linked to the national evaluation of the individual budget (IB) pilot projects (Glendinning *et al.*, 2009; Moran *et al.*, 2012) found that when carers of people with IBs were compared with carers of people using conventional social care services, IBs were significantly associated with positive impacts on carers' quality of life and, when other factors were taken into account, with improved social care outcomes for carers. These outcomes were achieved even though carers of people with IBs appeared to be spending slightly more time on care-related activities; in some instances this included new responsibilities for managing the IB. The study concluded that carers' involvement in, and satisfaction with, the service user's care/support plan were important indicators of improved outcomes for carers, partly because there could be opportunities to build into care/support plans services (e.g. respite) that could also benefit carers; and partly because carers derived indirect benefits from feeling that the person they supported was receiving better or more appropriate care.

The personal health budget evaluation aimed to conduct semi-structured interviews with 20 carers of personal budget holders, at three and nine months after the offer of a personal health budget. Nineteen carers were recruited, but only 13 of these took part in both interviews and were therefore, in principle, able to report on the impacts and outcomes of personal health budgets. In practice, three of the 13 were caring for people who still did not have a budget in place by the time of the nine-month interview. Further details of the recruitment and sample of carers are contained in Appendix A.

The 13 carers were supporting spouses (and often had been for many years in the case of those with progressive conditions), or severely disabled adult sons or daughters. They fell into three clusters:

- Carers of people with stroke or COPD (2 carers).
- Carers of people with long-term neurological conditions (LTNCs) (4 carers) – some of this group also had social care personal budgets.
- Carers of people eligible for NHS Continuing Healthcare (7 carers) – some of this group also received social care funding as part of a joint package.

These clusters broadly corresponded to differences in carers' expectations of personal health budgets (including the information they were given about the aims of the budget); their roles in decision-making about the budget; and the impacts the personal health budget had on them.

Both the latter two groups, and particularly those supporting relatives eligible for NHS Continuing Healthcare, were providing very substantial amounts of support, including personal care, specialised feeding and more or less constant supervision.



Only one carer, whose father was eligible for NHS Continuing Healthcare, did not live in the same household, but managed a team of paid carer workers from a distance; others had paid carers living in or visiting regularly several times a day. Only one carer was currently paid, through a local authority personal budget, for the care she gave her daughter at night and weekends. In some instances carers purchased additional paid care privately, over and above that funded through NHS Continuing Healthcare or local authority adult social care.

It is very important to bear in mind that this is a very small sample, drawn from less than half of the 20 PCTs taking part in the evaluation and including carers of only some of the health conditions included in the personal health budget pilots. Caution is therefore needed in generalising about the impact of personal health budgets on carers as a whole. Moreover, a surprisingly high proportion of carer interviewees were active in local condition-specific support groups or carers organisations; this may reflect PCTs' recruitment strategies and again strongly suggests that the sample is unlikely to be representative of the full range of people caring for personal health budget holders.

The carers were supporting people who had not been recruited to the main evaluation, so to some extent their accounts complemented those of budget holders themselves reported in this report. However, the focus in this section is on the impacts of personal health budgets specifically on their roles as carers: their initial expectations of the personal health budget and how it might affect them; their involvement in planning how the budget would be used and managed; how the implementation of the personal health budget pilots had affected their care-giving role; and the overall impacts of the personal health budget on them as carers.

## 7.2 First impressions and expectations of the personal health budget

The two carers of people with stroke/COPD had relatively low expectations of how the personal health budget might affect them as carers. From the information they had received, they understood the budget to be exclusively for the benefit of the person they were supporting:

The budget was to be used to pay for [husband's] health. [ ] Respite – I sort of raised that but [stroke co-ordinator] said it wasn't going to be used for respite.

A minority of the carers of people with LTNCs or eligible for NHS Continuing Healthcare also assumed, or had been told, that the budget was exclusively for the medical or other needs of the person they cared for:

I actually thought it was for his medical stuff.

However, the remainder of these latter two clusters of carers anticipated the budget would have at least some benefits for them as carers, as well as for the person they were supporting. Anticipated benefits included greater choice and flexibility over respite care arrangements, including back-up care arrangements if the carer was ill and unable to continue caring; being able to acquire specialised items of equipment

or treatments to make care-giving easier; or funding for items or services they were currently purchasing privately (but anticipated being unable to afford in the future):

Choice, I've never had a choice [over timing of respite], in the past things were just thrown at me and you take it or you don't.

It would give me a little bit of time to myself.

Indeed, for one or two of these carers, obtaining some (or more) respite care was a primary motivation for participating in the pilot; for example, one 75-year old man had been encouraged to join the pilot to seek some respite care by a Community Psychiatric Nurse who was concerned about the stress his wife's care was causing him.

The potential for the personal health budget to secure continuity was important for a few carers, particularly when the person they supported was moving from local authority-funded support to NHS Continuing Healthcare or from children's to adult services. For these carers, a personal health budget would enable them to continue employing paid care workers who already knew the disabled person; this was especially important when the latter had severe communication impairments or very specialised needs. The main hope of these carers was that the personal health budget would mean no change to their relatives' current support arrangements:

The reason I was joining [pilot] was so that we didn't lose anything.

All I really wanted was to guarantee that we could carry on with continuing to get funding for [wife's] live-in [paid] carers.

As well as direct benefits, some carers also anticipated indirect benefits derived from improvements in the quality of life of the person they supported:

Anything that [son] could get that would help him with his well-being will help me, because if [son] has a good day I have a good day; if [son] has a bad day [ ] it's a bad day for everyone.

I see my role as a carer as that if [wife's] happy then that's what it's all about.

Few carers anticipated any disadvantages for themselves from a personal health budget, although three carers were anxious about the potential workload of managing the budget on top of their existing care responsibilities:

Something else I've got to sort out [ ]. Carers get a lot of paperwork ... it's just another form.

### **7.3 Carers' involvement in deciding to try a personal health budget, care/support planning and managing the personal health budget**

The two carers supporting relatives with stroke/COPD were less involved in the decision to try a personal health budget; this was made either by their relative alone or jointly. In contrast, carers of people with LTNCs or eligible for NHS Continuing

Healthcare were much more likely to have taken the lead in deciding to try a personal health budget, albeit in consultation with the person they supported:

I discussed it with [wife] but if I'd said 'Let's not do it' she'd have said 'No'. So it was my decision.

[Son] really does leave everything to me. [Son] on the whole is OK about something if I say it's OK.

Similarly the two carers of people with stroke/COPD appeared less likely to have been involved in care/support planning, compared to those supporting someone with a LTNC or eligible for NHS Continuing Healthcare. Most carers in these latter two groups had been heavily involved in planning how the personal health budget would be used, either entirely alone or in consultation with the person they cared for:

Everything! I did all the phone calls, I did all the running around [...] I was acting on his behalf.

I suppose to be honest I organised it.

I've had total control of it.

One of these carers reported clear benefits from her lead role in planning how her son's budget would be used:

It did me good because I actually sat down over a few days and wrote out a list of things. ... When you're a carer you're so wrapped up in just trying to get through the day and the next day, you don't really think outside the box [ ] It kind of threw a spanner in the works for me really ... but it was good for me to think outside the box and it's made me think outside the box in other ways.

Only two of these latter two clusters of carers had had no involvement at all in planning how the personal health budget would be used, simply because they were unaware of any care/support planning process having taken place.

The extent to which carers' own needs were addressed in the budget holder's care/support plan seemed to follow a similar pattern. Carers of people with LTNCs, and particularly those eligible for NHS Continuing Healthcare, appeared more likely to have experienced the care/support planning process as at least partially addressing their own needs (as well, of course, as the needs of the person they were supporting):

It takes the pressure off of me [ ] I'll get a break which'll mean that I'm not tired all the time... and I think that's better for [son] as well that I'm not stressed out all the time.

I thought it was just purely and simply for [wife], not anything to do with me. [But] it sort of came around and I thought 'Well, if I want to go out on a Friday and I thought right, four hours, that's just a figure off the top of my head, I thought that gives me a nice bit of time, I can go out and go and visit me sister ...

Not all these carers were encouraged to consider their own needs as part of the care/support plan. One woman who had given up work to look after a daughter with a degenerative neurological condition said:

It [support planning] was all geared up around the needs of the child ... there's not much in it for the carer as well.

Carers' involvement in finding appropriate services to be funded through the personal health budget, or in the on-going management of the budget, seemed much more mixed. Some carers were adamant that they did not want the additional responsibility of recruiting paid carers, employing them or managing the personal health budget; indeed, these were conditions under which they agreed to try a personal health budget:

I don't want to be involved in messing about with paperwork or wages and things like that.

I did say when I took it out [signed up for personal health budget pilot] 'I don't want to end up having a big bag of money' [ ]. At the moment it [local authority-funded care] all goes through [ ] council, it just goes directly from them to the care agency and I did say I didn't want that to change.

I did say to them 'Look, I will need your help if this is finding people to spend time with [son] ... are you available for that?' and they said they would be [ ]. As long as I had that assurance I was happy.

One or two carers reported having received a great deal of help with the recruitment and on-going employment of paid carers to be funded by the personal health budget. One mother whose son had severe multiple impairments recruited a paid carer who already knew her son well:

... so it was just a case of applying for CRBs [Criminal Records Bureau checks] and doing a formal letter of employment. But I've had so much help with that, they've given me templates and drawn documents up for me and they've sent them off to the insurance company for me. [Payroll company] just tell me how much to pay and then they send me a payslip [ ]. I couldn't be without it.

Those carers who already had social care personal budgets, or were supporting people eligible for NHS Continuing Care that included some social care funding, tended to opt for building on the deployment and management arrangements they already had in place:

We [already] had some money coming through from social services and we'd already opened up a bank account for [wife] for that, and so they just said ... 'Well it can go into that'.

However, managing a personal health budget as well as funding from adult social care was not always straightforward, as section 7.4 will describe. A few carers felt they had been asked to take on additional responsibilities for managing the personal health budget somewhat against their will, or had not fully appreciated the additional work entailed:

It's not just the planning of the thing and getting it implemented, it's managing it because they want receipts and they want proof [ ]. So that's all on top ...

Another carer had included in his wife's care/support plan the costs of paying a carer to drive his wife to the extra physiotherapy she wanted, but was told 'Well, you're here, you can do it can't you?'

## 7.4 Personal health budget implementation and management issues affecting carers

Around half the carers interviewed had experienced difficulties or delays, in decision-making about the size of their relative's personal health budget, agreeing care/support plans, or setting up efficient payment arrangements. Indeed, as noted above, three of the 13 carers were supporting people who still did not have a personal health budget in place at the time of their nine-month interview. Again, this section focuses just on those issues that affected them as carers, primarily because of their responsibilities for providing and/or organising high levels of support for the person they were supporting. These problems affected carers supporting people with LTNCs or eligible for NHS Continuing Healthcare; they appeared to arise primarily from a lack of clarity about respective social care and health care responsibilities or from inordinate delays in agreeing care/support plans or making payments. The interviews also revealed some problems of equity between carers who were providing similar levels of support.

Some people with LTNCs were already receiving social care funding for paid care workers who were either employed directly by the carer through a direct payment, or provided by an agency that was reimbursed by the carer or the local authority. Here the personal health budget was offered in addition to the existing social care funding. Some of those eligible for NHS Continuing Healthcare also had some social care funding contributed to a joint-funded package; here the NHS Continuing Healthcare was converted to a personal health budget. Carers of both groups experienced difficulties because of a lack of clarity between local agencies about what could be funded from the 'health' and 'social' care elements of their support package. For example, one carer already receiving a social care personal budget wanted to use her son's personal health budget for gym membership and was offered a substantial discount if she enrolled him immediately. She had an underspend in her social care personal budget account but was not allowed to use this until her personal health budget came through because:

They said 'No, health's got to pay for that.' I said 'I'm a bit confused now, is that self-directed?' you know, and they said 'Yes, but that's a health [thing].'

Another carer supported her multiply impaired adult daughter whose care was funded by the local authority, NHS Continuing Healthcare and Independent Living Fund; these funds all went into a single bank account. She also had some local authority funding unspent (because of earlier delays in recruiting paid carers) and wanted to use this to buy a new electric wheelchair to make it easier to take her daughter out. However the local authority had refused, deeming this to be 'health' expenditure:

We can spend it on assistance as we want but we can't spend it on equipment ... It's sold as if you've got much more control ... but when it really comes down to it we've had all this trouble in getting it approved to buy an electric wheelchair which [daughter] has been assessed as needing.

Other carers reported problems when the arrangements for managing the personal health budget were inconsistent with those already in place to manage social care personal budgets or because of disputes over respective funding contributions. For example, one carer had been asked by her PCT to obtain references and CRB checks for a paid carer who she had been employing for 18 years to help care for her husband, when the latter started to get a personal health budget on top of his social care direct payment. She also experienced new difficulties with paying the paid carer; her social care funding was paid into a separate bank account from which she paid the carer, but her PCT had insisted on using a local payroll service:

Now I've got to ask someone else to sign a cheque to pay the man, rather than me signing the cheque [ ] We're not trusted with a cheque book of our own ... I've got to ring the lady [at the payroll service] and say the money that's required for the fortnight ... she is then going to write a cheque and then give it to me to give the [paid carer] ... it's almost like you're begging for it every fortnight. [ ] It really has been quite aggravating.

At her nine-month interview, this carer reported that on occasions the part-time payroll service administrator had been away, so she had had to pay her husband's care worker herself and reimburse herself (through a cheque made out to the paid care worker) when the payroll service cheque eventually arrived. Another carer, whose daughter had joint local authority and NHS Continuing Healthcare-funded support, had experienced great difficulties getting her daughter's personal health budget care/support plan approved because of disagreements between the PCT and local authority over what their respective contributions should fund. Although her daughter's care/support plan had apparently been approved, seven months later she still did not have a personal health budget and had tried to withdraw from the pilot. This carer also anticipated that accounting for how the personal health budget was used would be much more onerous than her previous experience of local authority direct payments:

I think it's going to be more time-consuming [than social care direct payments], definitely. [ ] They want receipts and they want proof every six months I will have to send in bank statements, slips of the money being used. So all that's on top [of the care I provide].

Although based on only a few cases, when the 13 carers' situations were compared, there appeared to be little relationship between the overall level of statutory support they received and the amount of care they provided. These inequities could be compounded by the route by which they had been recruited to the personal health budget pilot; and by the fact that some were receiving joint-funded support packages (from their local authority as well as the PCT). Thus one mother caring full-time for a son with severe multiple impairments received personal health budget funding for a part-time paid care worker and the equivalent of one week every other month respite care. In contrast, a man caring for a wife with advanced multiple sclerosis, who was eligible for NHS Continuing Healthcare funding, was able to employ two live-in carers

on a rotating basis. A third man, whose wife was immobile and needed peg feeding, received a personal health budget for just four hours respite each week. Finally, a woman supporting her son with severe learning disabilities was recruited to the pilot because her son also had diabetes; his personal health budget paid for him to join a gym, giving his mother virtually no respite care. These differences in levels of support were not necessarily reflected in the benefits that carers experienced from the personal health budget. However, if personal health budgets are to lead to greater transparency about the resources available to individuals, wider questions of equity between carers providing similar levels of care may become important, particularly when the funding of their relative's care is divided between NHS and local authority social care.

## 7.5 The impacts and outcomes of personal health budgets for carers

The impacts and outcomes of personal health budgets appeared to vary between the three clusters of carers. The two carers supporting relatives with stroke/COPD reported no benefits, as their respective partners' personal health budgets were tightly restricted only to items relating to their health care. Indeed, the partner of one of these carers had withdrawn from the personal health budget pilot as his budget was insufficient to purchase the specific piece of equipment he wanted, even though it would have made family outings and holidays much easier. The other's budget had been used to fund standard post-stroke rehabilitation services:

Zero – it hasn't made any difference to me whatsoever.

Among the carers of people with LTNCs and those eligible for NHS Continuing Healthcare, outcomes appeared to be mixed. As described in section 7.4, several had experienced considerable implementation difficulties and delays, particularly where the personal health budget formed part of an already complex funding package. For these carers, any potential beneficial impacts were offset by experiences of complexity and uncertainty:

At the moment, I feel it's not worth having the care for the amount of battle and fight I have to put into managing it.

Indeed, one carer had withdrawn from the pilot because of these difficulties and reported experiencing considerable stress himself, as he tried to protect his wife from problems relating to her support:

[ ] appalling – very long and off-putting. It's just another of the seemingly never-ending obstacles we have about trying to sort [wife's] care out.

For a few carers, specific outcomes of the personal health budget were difficult to identify, as the person they were supporting was experiencing other major simultaneous changes in their support arrangements: two carers were supporting teenage children moving from school and college to adult services; a few more were offered a personal health budget at the same time as the person they were supporting first became eligible for NHS Continuing Healthcare following a

deterioration in their condition. It was therefore not always easy to tease out the specific impacts of a personal health budget from these other changes.

Despite these challenges, among the remaining carers beneficial outcomes, both direct and indirect, could be identified. The main direct benefits were increases in the level of support carers received from paid care workers, which relieved some of their own responsibilities for providing hands-on care; and greater flexibility over respite care arrangements, including new opportunities to 'save' some funding in case additional respite was needed in an emergency. One man, who usually assisted paid care workers to lift his wife, said:

You're entitled to a bit more time off, so we can pay for another carer to assist [with lifting and transfer] on certain days.

Another man who cared full-time for his wife said:

Now I've got used to it, I quite look forward to it [ ] it really does make a fantastic difference because I'm actually free. [The break] blows all the cobwebs away and I enjoy meself for four hours and then I come back and we start all over again.

A prerequisite for these benefits, however, was that carers were happy with the alternative arrangements made for the person they supported; they spoke repeatedly of the 'peace of mind' of knowing their relative was enjoying the break as well. 'Peace of mind' could also be an important outcome of greater flexibility; one carer, for example, was reassured that she would be able to purchase additional support for her father if he needed extra care temporarily after a fall. Another, caring full time for a severely impaired son, said:

It has changed my life actually, because now I've got the flexibility of when I want respite. [ ] I can save up the hours for when it's a nice day and I can ask [paid care worker] to take [son] out.

A couple of carers supporting disabled adult children derived yet further 'peace of mind' from the fact that the personal health budget had enabled their son/daughter to begin going out and engaging in activities with someone other than their parent(s). They saw this as an important first step towards alternative arrangements when they were no longer able to provide care:

I like the fact that someone young is coming in and spending a bit of time with [son] so that's already a positive.

These examples illustrate the fact that benefits for carers and benefits for the personal budget holder may be both direct and indirect: carers could derive direct benefits from the budget, particularly in the form of (more flexible) respite arrangements; but they could also derive indirect benefits from improvements in the quality of life of their relative:

He's [severely disabled son] is going to be able to access more stimulation, he's with people his own age [ ] 'cos he's [ ] been stuck indoors with me 24/7. [ ] Being able to go out with my family without the worry of caring for [son], but with



the peace of mind that he is being well looked after and he's happy when he's not with me.

Anything that's positive in [son's] life is a positive to me [ ], it's definitely had an impact on my life as well, because he's just happier in himself, emotionally [ ]. He's not so emotionally needy, which has made my life a lot easier. So he seems to have more of his own life.

Finally, two carers noted additional, indirect benefits of the personal health budget processes. One carer reported receiving more help from NHS professionals in training the paid care workers who he employed to give the very complex care needed by his wife. Another was profoundly reassured by the fact that through the care/support planning process she had been put in contact with a local voluntary organisation that she anticipated would be able to support her in the future; she saw this as the main positive outcome of her son's personal health budget.

## 7.6 Summary

Based on this very small sample, carers' experiences of personal health budgets appear to vary considerably. Carers may derive relatively little benefit from personal health budgets which are tightly targeted just at the symptoms and health care of the person they support.

The potential for benefitting carers may be greater among those providing very considerable amounts of care to a relative with a progressive long-term neurological condition or eligible for NHS Continuing Healthcare, especially if their needs as carers are taken into account in the personal health budget care/support plan. The main benefits appear to be regular breaks for carers and/or greater flexibility over the timing of breaks, especially if this includes provision for emergencies. These benefits for carers depend on the person receiving care also being felt to benefit in some way from the break; if the latter also experiences improvements in their health, well-being or independence there may be further, indirect benefits for carers.

However, carers supporting people with progressive or very complex needs also appeared to be at risk of experiencing problems in the implementation of personal health budgets, particularly if they also received some social care funding. Arrangements seemed to work best when the personal health budget could simply build on existing employment and payment arrangements. However, carers could experience enormous stress where local authorities and PCTs could not agree on what was funded from their respective contributions, or required different payment or accountability systems.

Among this small sample, there appeared to be little equity in the overall level of support received by carers of people with very complex conditions.

## 8. Discussion and Conclusions

### 8.1 Introduction

This section pulls together conclusions from the interviews with budget holders nine months after the offer of a personal health budget and with carers of budget holders at three and nine months; identifies factors that appeared to affect their experiences of personal health budgets; and discusses wider issues relating to the implementation of personal health budgets.

The budget holders and carers interviewed for this report varied substantially in the severity and complexity of their health conditions. The latter ranged from a single, well-managed condition to multiple health problems, very severe impairments and progressive conditions. The interviewees were among the earliest people to be offered personal health budgets in the 20 pilot PCTs taking part in the in-depth evaluation. They are therefore not necessarily representative of all those offered a personal health budget, so caution needs to be exercised in drawing wider conclusions. The need for caution is further emphasised by the fact that nine of the 52 personal budget holders and three of the 13 carers of personal budget holders interviewed at nine months were supporting people who still did not have (or did not know whether they had) a personal health budget in place. The conclusions from this report on the impact of personal health budgets are therefore tentative and provisional; more robust evidence on the outcomes of personal health budgets will be presented in the final evaluation report to be published in Autumn 2012. Nevertheless, this section identifies a number of shorter- and longer-term issues surrounding the implementation of personal health budgets that warrant further attention.

The section first of all pulls together the evidence on why personal health budgets had positive impacts for budget holders and carers. It then discusses some of the implementation difficulties reported by interviewees. This latter discussion distinguishes between shorter-term difficulties that could be attributed to the early stages of the pilot programme and longer-term issues that will need to be addressed in any wider roll-out of the programme.

### 8.2 The positive impacts of personal health budgets

The most common uses of personal health budgets among this small sample were for physical exercise (e.g. gym membership, home exercise equipment); complementary and alternative therapies; and to employ paid care workers. Majorities of both personal health budget holders and carers reported positive impacts from their budget. Reported benefits included having (increased) choice over health care arrangements and services, including being able to access equipment or services not normally available through conventional NHS routes in order to better manage a health condition; greater flexibility (for example over the timing of treatments or provision of paid care in the home); improved physical and mental well-being; increased motivation and confidence; an improved social life; and access to more information about a health condition and how to manage it. In some

instances these benefits had exceeded budget holders' expectations. Three aspects of these benefits need highlighting.

First, interviewees reported how the personal health budget had encouraged them to focus, from the care/support planning process onwards, on the 'positives' – things that could help them feel better or improve their well-being. For people with long-term health problems, who constituted the majority of interviewees, this was a welcome contrast to many of their other encounters with health, welfare or benefits services, which tended to focus on more negative aspects of ill-health and disability. Having a personal health budget officer who set a positive tone at the start of the care/support planning process could be very important in encouraging this positive outlook; subsequent regular contact with personal health budget staff through formal or informal reviews could further sustain this attitude.

Secondly, positive impacts on physical and mental well-being were closely inter-related, so outcomes could be much wider than the specific health condition for which the budget had been awarded. For example, people who were offered budgets because of their mental ill-health and used them for gym membership reported better physical health as well. Conversely, people with chronic physical health problems who had been able to purchase equipment or treatments to help manage their symptoms better also reported improved mental well-being. However, these holistic benefits could be considerably reduced if budget holders were told they could use their budget **only** for the specific condition for which they had been recruited to the pilot, particularly if they had other, possibly more severe, chronic health problems. This suggests that, in the longer term, personal health budget assessment and other processes should adopt a holistic, well-being based approach, rather than a narrow focus on managing a specific condition or symptoms.

Third, personal health budgets could have major benefits for other family members too. Budget holders reported how, as their physical and/or mental health improved, or they became better able to manage pain and other symptoms, other family members became less worried or stressed. Some budget holders even reported improvements in the physical health of relatives and carers. Further evidence of these wider benefits came from some of the carer interviewees, who reported improvements in the quality of their own lives that derived indirectly from improvements in the health and well-being of the person they cared for. Conversely, where the personal health budget had major implications for carers (for example, when it was used to fund respite care that gave carers a break), carers also reported improvements in their relationship with – and therefore indirect benefits for – the person they supported.

These positive outcomes of personal health budgets were not experienced by all the interviewees in this small sample. Some felt their choice of how to use their budget had been unduly restricted by PCT panels or boards (see 8.3.2 below); by a lack of suitable local services; or by the low level of the budget.

It was not possible to identify any common patterns – for example, some condition groups being more likely to experience positive outcomes than others. Rather, outcomes varied both within condition groups and among budget holders recruited

from the same PCT. However, the interviews were able to identify a number of factors that seemed likely to optimise (or reduce) the benefits of personal health budgets. These factors were all related to the implementation of the personal health budget pilots.

## 8.3 Implementing personal health budgets – optimising outcomes

### 8.3.1 The role of information and support

Findings from these interviews with budget holders and carers highlight the importance of having clear information at all stages of the personal health budget process, and support to make and implement choices about how budgets are used. Clear information is needed about the level of the budget (including explaining how that level has been arrived at); what the budget can be spent on; and what to do subsequently if a health condition changes.

When interviewed three months after the offer of a personal health budget, the majority of interviewees had not known the level of their budget or, for those who did, how it had been calculated (Irvine *et al.*, 2011). Nine months after the offer of a personal health budget, a minority of interviewees still did not know whether they had a budget in place. Others continued to report misconceptions about the nature of the budget, in particular that their personal health budget came from a single, cash-limited ‘pot’ for which they had to compete with others; this made them reluctant to press for a (bigger) budget in case others were more ‘deserving’. A number also did not know the level of their budget, or how much was left for the remainder of the year; this meant they were also unable to assess whether the choices they had made constituted the best possible use of the resource, or whether the budget was sufficient for their needs.

Some interviewees reported making considerable efforts to find out about the progress of their budget, particularly whether their care/support plan had been approved or when equipment being funded from the budget would be delivered. However they spoke with frustration about being unable to contact anyone within the PCT who knew about their case. Such difficulties had led one or two interviewees to withdraw from the personal health budget pilot before the nine-month interview.

Some of these shortcomings may be attributable to the fact that interviewees were among the earliest to be offered personal health budgets in the 20 in-depth pilot sites; it is possible that the provision of information to later prospective budget holders subsequently improved. However, clear information about the size of the budget, how the amount has been arrived at and the fact that it is a personalised allocation are all fundamental to the principles of personal budgets in both health and social care and need to underpin any longer-term roll-out of the programme.

In addition, some interviewees identified a particular need for specialised information early in the care/support planning process. While many could relatively easily identify services or equipment that they expected would improve their health or general well-being, some were less sure about specific treatment options. They would have welcomed advice from health professionals (including consultants and physiotherapists) about the suitability or risks of alternative treatments before

commencing care/support planning, so they could rule out unsuitable options early on. Although completed care/support plans were scrutinised for clinical and other risks, this was too late and interviewees were demoralised when a completed care/support plan was turned down. In rolling-out personal health budgets, it may therefore be appropriate to consider how clinicians can be brought in to advise during the very early stages of care/support planning.

Interviewees were anxious about the longer-term future of their personal health budget, particularly if they felt their health had improved substantially, or if the budget was being used for items they would struggle to pay for themselves. Clearly some uncertainty about the future is inevitable with a time-limited pilot programme. However in the longer term, guidelines may be needed on the circumstances in which people stop being eligible for a personal health budget; how far should budgets be used to maintain health gain or prevent deterioration, for example? Any such guidelines will need to be made clear to prospective budget holders at the time of the initial offer, to ensure their expectations are realistic.

### **8.3.2 What personal health budgets can be used for**

A further area in which information is critically important concerns what personal health budgets can be used for. The interviews reported here indicate wide variations in permitted uses of personal health budgets. These variations were reflected in interviewees' reports of conversations with personal health budget staff during the care/support planning process, and of decisions by PCT panels or boards that subsequently scrutinised completed care/support plans. In some instances there appeared to be discrepancies between staff views and those of panels, with the former reported to have advocated on the budget holder's behalf to the latter. Budget holders were also generally unclear about the role of panels, which appeared to them to lack transparency or consistency and were reported to have turned down some care/support plans without any clear explanation.

For example, some items or services were reported in some pilot sites to have been deemed insufficiently health-related, or insufficiently related to a specific health condition, but were apparently allowed in others. Importantly, some interviewees were fully aware of these discrepancies, as they had accessed information about the personal health budget pilots through the internet and found examples of budgets being used for items they had had refused. Such variations may be attributable to differences in individual health needs, but interviewees did not report being given these reasons in explanation; they did not understand why a particular use had been approved or refused.

Interviewees' accounts suggested that in some instances very tight boundaries had been drawn around permitted uses of the budget. These restrictions variously failed to take into account additional chronic health problems experienced by budget holders, the roles of family members in providing considerable amounts of care and support, or the potential wider well-being benefits of personal health budgets. Budget holders and carers felt these restrictions had prevented them optimising the benefits of the personal health budget.

Having care/support plans turned down caused disappointment and frustration, particularly when interviewees were aware others had had similar plans accepted. Few interviewees were able to give clear reasons why their care/support plan had been refused and they could experience difficulties in identifying an alternative use for their budget. In the longer term, as experience of personal health budgets is built up among both NHS staff and budget holders, consideration could be given to developing guidelines or a (non-exhaustive) checklist of how budgets can be used.

Guidelines on approved uses also need to cover the boundaries between the personal health budget and related private expenditure. A number of interviewees valued their budget because it enabled them to obtain, through the NHS, services they had hitherto been purchasing privately and therefore reduced their own financial pressures. Others, however, incurred additional private expenditure as a direct result of their personal health budget. For example, they reported being told their budget was not allowed to cover some of the costs associated with employing a paid carer, such as the carer's admission to facilities where the carer needed to accompany the budget holder. In some instances interviewees had not known they could, or had not wanted to, ask for these additional costs to be covered; in other instances requests had been made but refused. Similarly, the delays experienced by a number of budget holders (see 8.3.6 below) prompted some to purchase urgently-needed equipment, treatments or services privately. These were consistent with their care/support plans and budget holders reasonably expected to be reimbursed. However, a few were subsequently told they were not allowed to make unauthorised purchases from their budget and so ended up out-of-pocket. Again, clear consistent information will be helpful.

### 8.3.3 Managing personal health budgets

A further area where clear, consistent information will be needed is about the management options for personal health budgets – a direct payment, managed by the PCT or managed by a third party. When interviewed at three months, some interviewees had not been able to recall being offered a choice about how their budget would be managed. Six months later, most knew how their budget was being, or would be, managed. Nevertheless, some of those who recounted making choices about the management of their budget had done so without detailed information about each option, or on the basis of inaccurate information.

On the whole, those who had opted for a direct payment were happy with this option, although there were sometimes initial difficulties in setting up bank accounts and occasional on-going problems where external payroll organisations were involved. Information and practical help with recruiting staff and on-going payroll administration were valued very highly. Budget holders and carers with experience of managing social care-funded direct payments valued being able to build on the employment and financial management arrangements they already had in place. It will be important for personal health budget staff to work closely with local authority partners to enable this to happen.

Where the personal health budget was managed by the PCT or a third party, budget holders appreciated not having the responsibility themselves; indeed, one or two carers had agreed to try a personal health budget only on condition that

responsibility for managing it was not added to their existing care responsibilities. However, considerable administrative problems could be experienced with this option, including substantial delays in items being ordered and/or delivered; regular fees not being paid; and reports by budget holders of being able to obtain the same equipment or service more cheaply themselves than when purchased by the PCT. There were several examples of budget holders who had spotted a special offer on an item agreed in their care/support plan and had asked the PCT if they could purchase this themselves and be reimbursed, but had been refused. It is not clear how far such inflexibilities and delays might be reduced as PCTs become more used to managing personal health budgets. If these are more than initial, pilot-related problems, then more flexible and responsive ways of managing budgets may need to be developed, in order to avoid what were sometimes distressing delays for budget holders.

Some budget holders who had initially opted for PCT or third party management of their budget were, by the time of the nine-month interviews, ready to consider moving to a direct payment. This is consistent with other research (Arksey and Baxter, 2012) showing that preferred personal budget management arrangements may change over time as people become more confident about the prospect of managing a budget themselves or, conversely, as changed circumstances make this an additional unwanted burden. Management options therefore need to be included in periodic reviews.

#### **8.3.4 Reviewing personal health budgets**

At the time of the nine-month interviews, many budget holders were unclear whether their contacts with personal health budget staff constituted a (formal or informal) review. As at the earlier interviews, most interviewees were happy with the choices they had made about the use of their budget and there had been few changes of use between the two interviews. It is not possible to infer how far this reflected genuine satisfaction or a lack of information and opportunity to alter how the budget was used. However, the anxiety that many interviewees felt about the continuation of their personal health budget (particularly when it had generated significant improvements in health and well-being, or when budget holders feared having to pay from their own money for services they now found indispensable) indicates that formal reviews are an urgent priority.

For many budget holders regular informal contacts with personal health budget staff were even more important. This was not just because of the difficulties some experienced in finding out about the progress of their budget. For those who already had a budget in place, regular informal contact could help to reinforce the positive impacts of the budget by maintaining a focus on agreed outcomes and sustaining budget holders' motivation.

#### **8.3.5 Personal health budgets and social care**

The majority of budget holders experienced no problems in managing their personal health budgets alongside any social care support they might also be receiving. However, some carers supporting people with progressive or very complex conditions were also receiving substantial social care personal budgets or a social

care funding contribution to an NHS Continuing Healthcare funding package. These groups appeared at significant risk of experiencing serious problems and delays if PCTs and local authorities could not agree on what should be funded from their respective contributions, or insisted on different payment or accountability mechanisms. Arrangements worked best when the personal health budget was simply integrated with the management and staffing arrangements that already existed. It will be important to ensure that, for these groups, implementing personal health budgets is consistent with guidance on joint working in the National Service Frameworks for Long-Term Conditions (2005) and NHS Continuing Healthcare (2009).

### 8.3.6 Delays and their impacts

Significant minorities of budget holders and carers had experienced inordinate, and apparently inexplicable, delays at all stages of the personal health budget process. Some delays could be expected in the early days of a new pilot programme and a few interviewees recognised this. However, delays could be damaging, particularly when prospective budget holders were unable to find out what was happening or obtain a realistic timetable. In particular, people who were less confident or assertive were unwilling to contact their PCT to find out what had happened to their budget and sometimes came to inaccurate conclusions about their eligibility for a budget. In contrast, some carers were articulate advocates on behalf of the person they were supporting, but experienced the need to press their PCT for decisions as an additional burden.

Delays in PCT panels approving care/support plans, setting direct payment arrangements in place, or procuring equipment or services were especially frustrating and damaging for people who felt any delay in starting new treatments could jeopardise their recovery, or who had rapidly deteriorating conditions. Frustrated by delays, some interviewees had bought equipment privately, hoping this would be reimbursed. Delays also had negative impacts on carers and other family members, if the budget holder became frustrated or if carers' opportunities for a break were delayed. As the pilot programme is rolled-out, processes for fast-tracking some personal health budgets may be necessary.

The only group of interviewees who would have welcomed a delay were those offered a personal health budget immediately following a stroke. At the time they were still unclear about the long-term effects of their stroke and were in any case already trying to absorb a lot of new information. They thought they would have been able to make better use of their personal health budget if it had been offered after their discharge from hospital.

## 8.4 Conclusions

It is striking that, even just nine months after the offer of a personal health budget, most people in this small sample were able to report some positive impacts on their health or wider well-being. However, problems with the implementation of the budget could detract from these positive outcomes. Some of these implementation difficulties are likely to reflect the challenges of setting up a new pilot programme and recruiting participants in a short space of time. It could therefore be expected that



they will diminish over time, as new systems become established. However, the interviews with budget holders and carers have also identified a number of areas in which improved processes are clearly needed, particularly if the pilot programme is rolled-out to all areas of England. In particular, clear information is needed on initial and on-going eligibility criteria for personal health budgets; the level of the budget and how this has been calculated; what the budget can be used for – particularly the boundary between narrow, health condition-specific uses and wider well-being objectives; and any linked private expenditure that is likely to be incurred. A second priority is for personal health budget processes to be speeded up and for clear information to be available about the timescales involved in making decisions. Thirdly, regular contact with personal health budget staff would provide help and reassurance with initial decision-making and opportunities to review those decisions over time as health conditions and other circumstances change. Finally, closer working with local authority partners is essential so that people with some of the highest level support needs and their carers are not subjected to protracted disputes over funding responsibilities or differences in management and accountability requirements. The current climate of renewed pressure to promote integration between health and social care offers an ideal environment to resolve these last difficulties.

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# Appendix A

## A.1 Overall design

This report is part of the in-depth strand of the personal health budgets evaluation. The in-depth strand as a whole has three main elements:

- Interviews with **budget holders** at approximately three months and nine months after taking up the personal health budget.
- Interviews with **carers of** budget holders at approximately three months and nine months after taking up the personal health budget.
- Interviews with budget holders receiving two **specialist services**: maternity and end-of-life care.

This report covers the second round of interviews with budget holders, approximately nine months after taking up the offer of a personal health budget, and the interviews with carers at approximately three and nine months after taking up the personal health budget.

For full details of recruitment and sampling of budget holders, see Irvine *et al.* (2011).

## A.2 Sample of personal health budget holders

Six health conditions were covered by the budget holder sample: diabetes, chronic obstructive pulmonary disease (COPD), stroke, long-term neurological conditions (for example, multiple sclerosis, Parkinson's), mental health conditions and people eligible for NHS Continuing Healthcare. Fifty-eight budget holders were interviewed at three months and 52 at nine months. Table A.1 gives the numbers by condition group.

**Table A.1 Numbers of budget holders interviewed**

<b>Condition</b>	<b>3 months</b>	<b>9 months</b>
COPD	7	6
Diabetes	6	5
LTNC	13	10
Mental health	9	8
NHS Continuing Healthcare	15	15
Stroke	8	8
<b>Total</b>	<b>58</b>	<b>52</b>

### A.3 Conducting the interviews with budget holders

The majority of interviews were conducted face-to-face in the budget holder's home, using a semi-structured topic guide. A very few interviews were conducted by telephone. The main topics covered were:

- The impacts of the personal health budget on the health, well-being and quality of life of the budget holder (and other family members).
- How the personal health budget had been used and budget holders' reflections on the choices they had made.
- Budget holders' satisfaction with the level of their personal health budget.
- Reflections on the chosen management options for the personal health budget.
- Experiences of the implementation of personal health budgets.

Interviews typically lasted 60-90 minutes, but several approached two hours. Sometimes people chose to take a brief break but in most cases interviews continued uninterrupted for their duration. The researchers used the topic guide flexibly. While key themes were covered with all participants, certain questions or probes were omitted where not applicable to that person's circumstances or experience.

In a number of cases a third party was present during the interview and often contributed a substantial amount to the conversation or acted as a proxy interviewee.

Interviews were digitally recorded with the participant's consent. Some participants showed printed papers to the researcher during the interview, for example, assessment forms, care/support plans, financial information or correspondence from the personal health budget lead or care navigator. These documents were discussed during the interviews as relevant but detailed information from such paperwork was not recorded and copies were not taken away by the researcher.

### A.4 Recruitment and sample of carers

The evaluation aimed to conduct semi-structured interviews with 20 carers of personal budget holders, at three and nine months after the offer of a personal health budget. Although a number of carers had consented to participate in the main evaluation as proxy respondents for budget holders, they were not considered appropriate to interview, as they had not consented to participate as carers in their own right. However, recruitment of carers as respondents themselves to the main evaluation was delayed until some time after the start of the evaluation. Therefore, in order to be able to conduct both the three- and nine-month interviews within the overall timeframe of the evaluation, it was necessary to select the sample for these interviews from a limited number of the earliest carer recruits. Consequently, it was not possible to include in the sample carers supporting personal budget holders with the full range of conditions covered by the pilots, nor carers from all the PCTs involved in the evaluation. Nineteen carers were recruited for the semi-structured interviews, a majority of whom were supporting personal budget holders with long-term neurological conditions (LTNC) or eligible for NHS Continuing Healthcare.

Subsequently there was some attrition from the sample: five carers withdrew from the personal health budget pilot and/or the evaluation before the nine-month interview and one who was interviewed at three months could not be recontacted at nine months. Table A.2 summarises the sample.

**Table A.2 Carers recruited to the in-depth study**

<i>Carers who were supporting relatives with:</i>	<i>3 month interview</i>	<i>9 month interview</i>
Stroke <sup>1</sup>	3	1
COPD <sup>2</sup>	2	1
LTNC <sup>3</sup>	7	4
NHS Continuing Healthcare	7	7
Total	19	13

1. One of these had a long-term neurological condition as well as stroke.
2. One of these had multiple health problems, including arthritis, as well as COPD.
3. Two of these had additional health problems, including diabetes and Aspergers Syndrome.

Because this report focuses specifically on the impacts and outcomes of personal health budgets, the analysis concentrates only on the 13 carers who took part in both interviews. Even so, at nine months one of these carers had recently withdrawn from the personal health budget pilot; one was caring for someone still waiting to receive a personal health budget; and one was not sure whether a personal health budget had been awarded or not.

As with the main sample of budget holders, carers were interviewed using a semi-structured topic guide. The three-month interviews focused on carers' early knowledge of personal health budgets; their role in the decision to try a personal health budget and in planning, so far, how it would be used and managed. The nine-month interviews explored carers' experiences with the overall implementation of the personal health budget; their satisfaction with the roles they had been able to play in planning how the budget was to be used; and the direct and indirect impacts of the budget on their carer role. Both rounds of interviews were conducted face-to-face or by telephone; were digitally recorded and transcribed; and subsequently analysed using the Framework method to identify patterns and themes of interest and common experiences.

## **A.5 Data analysis**

The completed interviews with budget holders and carers were transcribed in full. Data (summaries and quotations) were extracted from each transcript and placed in a template organised by themes by the researcher who had conducted the interview. The themes included in the template followed closely the structure of the topic guide. The thematic analysis was supported using MaxQDA. The themes were written up for the sample as a whole, with each researcher taking lead responsibility for writing up a number of themes.