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Personal Health Budgets: Early experiences of budget holders

Fourth Interim Report

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DH 2478

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

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Contents

| | |
|---|-----------|
| Acknowledgements | i |
| Contents | ii |
| Executive Summary | v |
| 1. Introduction | 1 |
| 1.1 Background – personal health budgets and the evaluation | 1 |
| 1.2 The in-depth sub-sample | 3 |
| 1.3 Structure of the report | 3 |
| 2. Health conditions and healthcare prior to personal health budgets | 4 |
| 2.1 Health conditions and healthcare | 4 |
| 2.2 Satisfaction with healthcare before the personal health budget..... | 4 |
| 2.3 Summary | 5 |
| 3. Deciding to take up a personal health budget | 6 |
| 3.1 Finding out about personal health budgets | 6 |
| 3.2 Deciding to try a personal health budget..... | 7 |
| 3.3 Adequacy of information in deciding to take up a personal health budget | 8 |
| 3.4 Summary | 9 |
| 4. The level of the personal health budget | 10 |
| 4.1 Knowledge of level of personal health budget..... | 10 |
| 4.2 Understanding how the personal health budget was calculated | 11 |
| 4.3 Adequacy of level of budget..... | 11 |
| 4.4 Summary | 12 |
| 5. Planning how to use the personal health budget | 13 |
| 5.1 Experiences of care/support planning processes | 13 |
| 5.2 Deciding how to spend the personal health budget..... | 13 |
| 5.3 Uses of personal health budgets..... | 15 |
| 5.4 Identifying and sourcing provision | 16 |
| 5.5 Help, support and information in planning how to use the personal health budget..... | 17 |
| 5.6 Satisfaction with outcomes of care/support planning..... | 18 |
| 5.7 Summary | 19 |
| 6. Management of the personal health budget | 20 |
| 6.1 Choosing how to manage the personal health budget..... | 20 |
| 6.2 Personal budgets for social care and health | 22 |

| | | |
|-------------------|--|-----------|
| 6.3 | Summary | 22 |
| 7. | Anticipated and early outcomes of personal health budgets | 22 |
| 7.1 | Early outcomes of personal health budgets | 23 |
| 7.2 | Personal health budgets and personalisation..... | 23 |
| 7.3 | Anticipated difficulties with personal health budgets..... | 24 |
| 7.4 | Summary | 25 |
| 8. | Conclusions | 25 |
| | References..... | 28 |
| Appendix A | Research methods and sample | 29 |
| A.1 | Overall design..... | 29 |
| A.2 | Target sample..... | 29 |
| A.3 | Ethical considerations | 30 |
| A.4 | Constructing the sample | 30 |
| A.5 | Preparing for recruitment and interviewing..... | 31 |
| A.6 | Recruitment and consent | 32 |
| A.7 | Achieved sample | 33 |
| A.8 | Conducting the interviews..... | 34 |
| A.9 | Data analysis | 35 |

Executive Summary

Personal health budgets are being piloted in English primary care trusts (PCTs) between 2009 and 2012. This evaluation report looks at the early experiences of a small subsample of budget holders and their representatives. It reports in-depth interviews with 58 people from 17 PCTs, around three months after the offer of a personal health budget, about their experiences of personal health budgets so far.

Main findings

- Some interviewees had already experienced positive outcomes from their personal health budget. These included being able to access treatments, services or equipment not available through the NHS; having greater choice and control over when their care and support is provided; and being able to employ specialist staff. Many other interviewees anticipated similar benefits once their personal health budget was operational.
- These outcomes were expected to lead to better health, improved morale and motivation, and enhanced social inclusion. Sometimes other family members were also expected to benefit, if their care responsibilities were reduced. Personal health budgets could also bring indirect benefits, for example if assessment processes led to medication reviews or in-depth discussions of health problems with a health professional.
- The characteristics of people offered personal health budgets varied widely. Some had very complex health conditions affecting all aspects of their daily lives; others had stable, well-managed health problems. These differences affected their experiences of the personal health budget.
- Some interviewees had been offered personal health budgets in response to a specific unmet need; they sometimes had little interest in the wider aims of the pilot or in considering alternative uses for the budget. Others who were familiar with social care personal budgets were aware of the policy aims of increasing choice and control; they tended to use their budget to maintain an existing support package.
- Information about how personal health budgets could be used was crucially important for prospective budget holders. People intending to use their budget for a specific unmet need were sometimes unaware that other uses were possible; others needed considerable encouragement to think how the budget might best be used.
- Few interviewees knew how much their budget was before they began planning how to use it, or how the level of the budget had been calculated. Many reported they had not been given a choice of how their budget would be managed.

Context

Personal health budgets are central to developing more personalised healthcare in England. Personal health budgets offer individuals choice over which care and services they receive and control over the money spent on their healthcare. After an initial assessment, an individual is told how much money is available and decides how to use this money to meet health and wellbeing outcomes. These plans are agreed with and signed off by the PCT. The budget can be held by a health professional; by an independent third party on behalf of the patient; by the patient as a cash direct payment (in certain approved localities); or a combination of these.

Personal health budgets are being piloted in 64 PCTs from 2009-2012; 20 of these PCTs are taking part in an in-depth evaluation (see www.phbe.org.uk). The evaluation aims to find out whether personal health budgets lead to better health and social care outcomes, compared to conventional service delivery. The evaluation is examining the impact of personal health budgets on people with long-term conditions (including chronic obstructive pulmonary disease, diabetes and neurological conditions); stroke; mental health conditions; and those eligible for NHS continuing healthcare.¹

An important strand of the evaluation examines patients' experiences. It involves semi-structured interviews with a sub-sample of patients, around three months after accepting the offer of a personal health budget and again about six months later. The three month interviews reported here were conducted early in the implementation of the pilots, with some of the first patients to be offered personal health budgets. These patients may not be wholly representative of those subsequently recruited to the pilots. Some of their experiences may also be atypical, because the pilot sites were not fully operational at that stage and were still working out how to implement personal health budgets. These experiences, and the rest of the evaluation, will inform the further implementation of the pilots and subsequent rollout of personal health budgets.

Next steps

The same sub-sample of patients will be interviewed again, six months later, to find out about the impacts and outcomes of personal health budgets. A further interim report of these interviews will be submitted to the Department of Health in April 2012. A full report of the whole evaluation will be submitted to the Department of Health in October 2012.

¹ The impacts of personal health budgets on maternity care and end of life care are also covered by the evaluation, but are not included in this report.

1. Introduction

1.1 Background – personal health budgets and the evaluation

The piloting of personal health budgets is 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* (HM Government 2010) and further reiterated in the Government's response to the report of the NHS Future Forum (HM Government 2011).

Personal health budgets aim to give individuals more choice about the care and services they receive, by giving them more control over the money that is spent on their healthcare. After an assessment of needs, an individual is told how much money is available to purchase services and care and draws up plans for using the budget to meet their health and wellbeing outcomes. These are agreed with and signed off by the PCT. The money can be deployed as a notional budget held by a health professional; held by another third party on behalf of the patient; taken as a cash direct payment held by the patient (currently in authorised pilot sites only); or a combination of these.

Personal health budgets are new to the NHS, and they involve major cultural and organisational changes for services, professionals and patients. Evaluating the pilot projects is therefore very important. The Government will use the findings from the evaluation to inform a wider rollout of the initiative after October 2012.

In 2009, the Department of Health invited PCTs to become pilot sites for personal health budgets and an independent evaluation was commissioned. Twenty PCTs were selected to provide in-depth data for the evaluation, with the other pilot sites contributing to a wider evaluation. The in-depth evaluation is examining the impacts of personal health budgets on people with long-term conditions (including chronic obstructive pulmonary disease, diabetes and neurological conditions); stroke; mental health conditions; and those eligible for NHS continuing healthcare. It will also examine the use of personal health budgets in maternity and end of life care.

The evaluation aims 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). An important strand of the evaluation explores the experiences of patients offered

personal health budgets. It therefore includes semi-structured interviews with a sub-sample of patients conducted around three months after accepting the offer of a personal health budget, and again about six months later. This report presents findings from the three month interviews; a further interim report covering the nine month interviews will be published in April 2012.

This first round of semi-structured interviews explored:

- The decision to accept the offer of a personal health budget and factors affecting that decision.
- The information and other help sought, available and still needed about personal health budgets at the time of the offer and subsequently.
- The processes of deciding how to deploy and spend the personal health budget.
- The roles of health professionals and others in decisions about how to use the personal health budget and deployment options.
- Any early subjective outcomes.

In reading this report, it is important to bear in mind that personal health budgets are still being piloted; finding out what personal health budget processes work best for which groups of patients is an important aim of the evaluation. The patients participating in the interviews reported here were interviewed early in the implementation of the pilots, with some of the first patients to be offered personal health budgets in the 20 in-depth evaluation sites. Each of these pilot sites is devising its own approach to implementing personal health budgets. Given the organisational challenges in implementing personal health budgets (Jones *et al.* 2010), some of the experiences reported here may not be typical of the pilots once they are fully operational. For example, early budget holders may experience processes of care/support planning as more protracted and uncertain than when schemes have been fully implemented. Moreover, these early prospective personal health budget holders may themselves not be typical of the patients who are subsequently offered personal health budgets in the pilot sites. In addition, few of the budget holders had begun to receive services, care or equipment funded from their personal health budgets by the time of these early interviews. The experiences reported here should not, therefore, be assumed as representative of all those taking part in the pilot projects, and even less so of those who may be offered personal health budgets in the future, once the initiative is rolled out beyond the pilot stage.

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.

1.2 The in-depth sub-sample

Fifty-eight people from the larger sample of people recruited to the evaluation took part in the in-depth interviews, around three months after they had been offered a personal health budget. Interviewees were sampled from 17 of the 20 pilot sites involved in the in-depth evaluation (these ranged geographically from Hartlepool and Stockton-on-Tees in the North East of England to Torbay in the South West of England). Interviewees included men and women, aged from their teens to 80-plus years old, and covered all the patient groups involved in the in-depth evaluation (apart from those receiving budgets for maternity or end of life care). Many interviewees, regardless of the severity of their condition, wished to have a spouse or other relative with them during the interview; these relatives often contributed additional data to the interview. In the few instances in which a personal budget holder was unable to participate in the interview her/himself, the interview was conducted with a proxy (in most of these cases this was a family member).

The sample was not intended to be representative of all budget holders involved in the pilots, so the findings of this report cannot necessarily be generalised to the wider population. While we do not give exact numbers or percentages of interviewees who reported specific experiences with the planning and use of their personal health budgets, the report does indicate the broad prevalence of particular experiences – for example, whether it was widespread or reported by a majority of interviewees.

Details of the recruitment strategy and sample are contained in Appendix A.

1.3 Structure of the report

The report follows interviewees' experiences of being offered, and deciding how to use, a personal health budget. The next section contextualises these experiences by reporting on the health problems and healthcare received prior to the offer of a budget. The reasons for accepting a personal health budget are discussed in Section 3. The level of the personal health budget is described in Section 4. Section 5 describes interviewees' experiences of planning how to use their budget. Section 6 examines their knowledge of the budget management options. Finally, Section 7 considers the early outcomes of personal health budgets.

2. Health conditions and healthcare prior to personal health budgets

This section describes the health status of the sub-sample; the services received prior to the offer of a personal health budget; and the satisfaction of the sub-sample with these services. These factors are likely to shape responses to, and expectations of, a personal health budget.

2.1 Health conditions and healthcare

All the health conditions (diabetes, COPD, stroke, neurological conditions, mental health and conditions requiring NHS continuing healthcare) included in the in-depth evaluation were represented in the sample. Many interviewees had additional health problems, including arthritis, osteoporosis, back and joint problems, angina and high blood pressure; these were sometimes as significant as their personal health budget condition. Most interviewees had had these conditions for many years; only a few had experienced recent onsets that had prompted the offer of the budget.

The impacts of these problems on interviewees' daily lives varied widely, from well-managed conditions that imposed few restrictions to profound limitations and needs for assistance with all activities of daily living. Tiredness, restrictions on leaving the house and reduced motivation and concentration were common. Some people, with mental health conditions or Multiple Sclerosis for example, reported that stress exacerbated their health problems.

Similarly, healthcare regimes varied considerably, from simple medication and routine reviews by healthcare professionals to onerous regimes including injections, physiotherapy and non-NHS alternative therapies. Several interviewees had equipment to help manage their healthcare at home. People with long-term neurological conditions, some mental health conditions and conditions entitling them to NHS continuing healthcare commonly had regular home visits from specialist or district nurses, plus social care support. Self-management regimes included monitoring symptoms and adjusting medication accordingly, as well as diet, exercise and avoiding infection risks.

2.2 Satisfaction with healthcare before the personal health budget

Of those who had regular healthcare regimes in place before the offer of a personal health budget, most were reasonably satisfied with these and positive about the healthcare professionals they dealt with, particularly specialist nurses who were highly praised. Other sources of satisfaction

included being able to attend a day centre for classes, having a helpful GP and having easy access to a valued Care Team. Dissatisfactions focused on the unreliability and inflexibility of home care services; occasionally unsympathetic healthcare practitioners; and occasional poor hospital inpatient experiences. A minority of interviewees had been denied desired treatments (for example, specialist physiotherapy on the grounds of cost) through the NHS; felt the care they had been offered did not meet their needs; had to pay prescription charges for drugs relating to a long-term condition; or had difficulties obtaining regular supplies of essential personal care or medical equipment. A few interviewees felt frustrated at a lack of 'active' input from the NHS in trying to improve their health, or that their package of care was not really 'working' for them.

Several people had tried to address such dissatisfactions; a few had succeeded in changing their medication or transferring to a more convenient hospital. However, unsatisfactory outcomes were more common, leading interviewees to change a provider or practitioner; stop using a service; or pay for private treatment. More commonly, interviewees were reluctant to complain or simply did not know this was possible.

Around half the sample had incurred, or were currently incurring additional healthcare costs. These included the private purchase of treatments such as acupuncture, massage, reflexology, chiropody, physiotherapy and counselling. Other private expenditure aimed at improving the individual's health included gym membership, health-related social activities, nebulisers, blood glucose monitors, wheelchairs, home exercise equipment, dietary supplements, domestic and personal care and home adaptations. Around half those paying privately justified this as beneficial and therefore '*worth it*', or did not expect the NHS to fund less '*conventional*' treatments. The others were less happy at being unable to obtain necessary treatments from the NHS and worried about the longer-term costs. Some of those currently paying privately saw the personal health budget as a way of covering these costs.²

2.3 Summary

There were wide variations in the type, severity/complexity and duration of health conditions in the sub-sample. Not all interviewees had severe health conditions and many managed their symptoms effectively. Others had additional health problems as serious as those for which they had been offered a personal health budget. There was varying satisfaction with

² The impact assessment for personal health budgets noted at the outset of the pilot programme that, as the NHS becomes more flexible and responsive, people who currently pay privately for some items aimed at improving their health status may be attracted back to the NHS. The impact assessment is available at http://www.dh.gov.uk/en/Publicationsandstatistics/Legislation/DH_094806

healthcare provision prior to the personal health budget; around half the interviewees were paying for health-related items/services privately. All these factors would shape experiences and impacts of personal health budgets.

3. Deciding to take up a personal health budget

This section describes how interviewees first heard about personal health budgets, their understanding of the aims of the pilots and their reasons for taking up a personal health budget. Of particular interest is the information that was available at this time and any unmet information needs.

3.1 Finding out about personal health budgets

Around half the interviewees first heard of personal health budgets through specific pilot recruitment activities. Some were invited to have a one-to-one talk with a healthcare professional, others to attend a meeting. The remaining interviewees had first heard from other sources or after they had mentioned a specific unmet need or dissatisfaction with their current care to a healthcare practitioner. The latter was more common among people receiving NHS continuing healthcare, recovering from stroke or with mental health problems; here, a personal health budget was suggested as a way of resolving the specific problem. A few people in both groups were offered personal health budgets not to replace or supplement existing healthcare arrangements but in the course of setting up entirely new treatments and care, particularly post-stroke rehabilitation and NHS continuing healthcare packages.

These different routes shaped the processes of learning about personal health budgets. Those invited to participate in the pilot projects received both general and personally tailored information, including leaflets and information packs with examples of how personal health budgets could be used. They were therefore more likely to know about the broad aims of personal health budgets as being to improve their '*quality of life*', to enable a better '*lifestyle*' or to '*make you feel better in yourself*'. Other people, particularly those eligible for NHS continuing healthcare, reported being told about personal health budgets in response to a specific need or dissatisfaction with their current care arrangements.

Some people understood the principle of a personal allocation of funds as '*an allotment to your name*'; others thought they were drawing on a general fund rather like a grant-making scheme, so that if they did not use the money it could be allocated to someone else. Overall, around a quarter of interviewees used language reflecting the policy aims of personal health budgets, including

greater choice, personalised services, independence and autonomy. Some made connections between such aims, more effective healthcare and improved outcomes.

About half the interviewees had no worries or reservations about trying a personal health budget. Among the rest there were a variety of anxieties, although no single worry seemed widespread at this early stage. Anxieties (each expressed by one or two interviewees) included whether the personal health budget would affect existing healthcare treatments; the '*hassle*' involved; the size of the budget; how they would decide what to use the budget for; and whether their chosen use would be approved. Other concerns related to the sustainability of a pilot scheme and the funding of their healthcare after the pilot ended. A few people whose health problems were well-managed felt uncomfortable at getting '*something for nothing*' and thought others were more deserving of additional financial help. All these concerns could be addressed by fuller information at the point of first offering a budget.

Such early anxieties were often linked to a general lack of information about personal health budgets; subsequent discussions with healthcare professionals had usually provided reassurance, again underscoring the importance of detailed early information.

3.2 Deciding to try a personal health budget

For most people, deciding to try a personal health budget was linked to a clear idea about what they might use it for. For those who were told about budgets in response to a particular need or gap in provision, deciding to have a budget was directly linked to meeting this need: '*it was an opportunity I couldn't refuse because it got me out of dire straits a lot quicker*'. People eligible for NHS continuing healthcare saw a personal health budget as offering greater choice, control and flexibility over who provided their care and when, by being able to employ their own carers. Indeed, for those recently eligible for NHS continuing healthcare, a personal health budget appeared to be the default offer; no actual decision was involved. A minority of interviewees had decided to try a personal health budget simply because it seemed a good idea and there was '*no harm*' giving it a try: '*I just feel that the way things are for me and the way life is for me, that anything that can improve my quality of life is worth trying*'. They felt they had '*nothing to lose*' and it would be '*silly*' to turn down what seemed like a positive offer.

Overall, interviewees eligible for NHS continuing healthcare or with more complex, disabling conditions were more likely to see personal health budgets as a means to exercising greater choice and control: '*it is...giving me greater*

independence ...being more empowered to make choices for care solutions that aren't limited to what statutory services can or can't do'. Those with less complex, better managed, conditions saw the budget as an opportunity to try a new service or equipment, as an addition rather than an alternative to their existing healthcare package. Deciding to try a personal health budget was therefore relatively low risk and something of a 'no brainer'.

Because most interviewees could identify a potential use for a personal health budget, they had made the decision to try one fairly quickly, either on first hearing about the pilot or after just one or two discussions with a healthcare professional.³ Only a few people had taken longer to decide and again this tended to be contingent on thinking of a suitable use for the budget.

3.3 Adequacy of information in deciding to take up a personal health budget

Interviewees were asked about the adequacy of the information they had received about personal health budgets by the time they decided to try one. This is a key area for the new policy; experience from the implementation of personal budgets in social care underlines the importance of budget holders having sufficient information to make decisions. However, the level, and format, of information required can vary significantly between individuals.

Most people thought the information they had been given prior to taking up a personal health budget was generally adequate. A minority did not feel so well informed; some commented that the healthcare professional who had first introduced them to personal health budgets did not seem to know much about them either⁴. Even so, this initial information was often sufficient to interest them in attending a group or one-to-one meeting with a more knowledgeable professional. Further details of the pilots were usually gained through these subsequent one-to-one contacts, sometimes accompanied by written information.

Generic leaflets or brochures were considered useful in giving a general overview of personal health budgets, but interviewees often had difficulty relating these to their own circumstances. More commonly, interviewees preferred face-to-face discussions with healthcare professionals, where more

³ During the three month interviews, a few people were uncertain about whether to continue with their personal health budget. Their experiences and outcomes will be explored in the second wave of in-depth interviews ninth months after the offer of a budget. The results of these interviews will be reported in the 5th interim evaluation report.

⁴ Some people understood that personal health budgets were a new initiative and therefore practitioners were themselves still getting to grips with the scheme.

detail could be given⁵: *...if they had a one to one doing it instead of just giving us all them forms to fill in and, you know, so we go, I could go more ...into it with the person*. Very few had sought additional information from the internet or from other professionals they knew well, such as their GP.

The amount of information described as *'adequate'* varied considerably. Those intending to use the budget to meet a specific pre-identified need were much less interested in having comprehensive information about the aims of personal health budgets. Knowing they could pull out of the pilot if they changed their mind also seemed important in making this decision without full information⁶. Some interviewees recalled it had been difficult to retain or seek further information because they had been introduced to personal health budgets when they were acutely unwell.

Moreover, by the time of the three-month interviews, several people had unanswered questions about their personal health budget; often these had arisen since deciding to take up the budget. The most common need for more information was about the ways that personal health budgets could be used, particularly if initial plans for using the budget had turned out not to be possible. Interviewees wanted lists of possible uses or examples of how other people in similar circumstances had used their budget (see Section 5). Other, less common, gaps in information concerned the level of the budget (see Section 4); deployment options; and the flexibility of the scheme over time. However, none of these subsequent gaps had prompted interviewees to reconsider their decision to have a budget; rather they may have influenced the speed and effectiveness of planning how to use the budget (see Section 5).

3.4 Summary

Some people had been introduced to personal health budgets through specific pilot recruitment activities; others had heard about them when they had spoken to a health professional about an unmet need or some dissatisfaction with the services they currently received.

People had varied understandings of the aims of personal health budgets, with different interviewees emphasising health treatments, broader wellbeing, an additional source of funding and enhancing choice and control. A few

⁵ Other comments from participants about preferred communication methods included preferring face-to-face rather than telephone contact and appreciating the option of corresponding by email rather than telephone.

⁶ All the people whose experiences are reported here had decided to try a personal health budget; it is possible that gaps in information may have deterred others in the pilot sites who were offered a personal health budget from taking up the offer.

people appeared rather confused still about the design and purpose of the pilots.

Most interviewees could identify ways in which they might benefit from a personal health budget and this was closely linked to the decision to try a budget. People with complex conditions, or who were already receiving home nursing or social care, saw personal health budgets as a way of achieving greater choice, control and flexibility. Those with less complex conditions saw the budget as a chance to try a new treatment or item of equipment or to offset the costs of things they were already purchasing privately, without the rest of their healthcare being affected. For the latter group, personal health budgets appeared to present little risk and no apparent drawbacks.

Most people felt that they had sufficient information in deciding to try a personal health budget, although actual levels of information varied considerably and additional queries sometimes arose over time. The variety and duration of participants' information needs suggests the importance of a flexible and individualised approach to information, advice and support for budget holders, with ongoing opportunities for further queries to be answered.

4. The level of the personal health budget

Transparency is central to personalisation in health and social care. A basic principle of personal budgets is that holders should know the approximate level of their budget so they can plan its use appropriately. Ideally, they should also know how this amount has been calculated. Overall, among the interviewees there appeared a lack of transparency about the levels of personal health budgets and how they had been calculated.

4.1 Knowledge of level of personal health budget

Just under a third of interviewees said they had been told the amount of their personal health budget in advance of any care/support planning taking place. Some were told this was a pre-set amount; others were not sure whether the level of the budget was fixed or not. Slightly more common was for interviewees not to have learned about the level of their budget until well after they had started planning how to use it. For one participant it seemed that care/support planning and budget setting occurred simultaneously. A few interviewees remained unclear about the level of their budget three months after the initial offer, sometimes even where their personal health budget was up and running. A few interviewees did not conceptualise the item or service

procured for them as having come from their personal health budget, but as a one-off grant for the specific item.

4.2 Understanding how the personal health budget was calculated

Interviewees' knowledge of how their personal health budget had been calculated varied widely.

Around a quarter of interviewees thought they understood how their personal health budget had been calculated, but the basis for these calculations varied widely. Some people thought the budget had been worked out after they had completed their care/support plan so that it reflected their identified needs. Others reported that the level of their budget reflected the cost of the services and/or items they planned to use the budget for. A third group understood their budget had been calculated with reference to the cost of their previous NHS service use. A fourth group thought their budget was set at a standard amount for their particular condition. Some interviewees had no knowledge at all of how their budget level had been set, and speculated on whether it was a standard amount for their condition or specific to their individual needs.

More commonly, people did not know how their budget had been worked out. Most of these interviewees would, to varying degrees, have been interested in knowing because, for example, it would have helped in planning their use of the budget. For the others in this group, understanding how their budget had been calculated was apparently not particularly important. Some recalled being told by a healthcare professional but had forgotten; others with only a vague understanding nevertheless thought they knew enough.

4.3 Adequacy of level of budget

Overall, few interviewees had any preconceptions about how much their budget would be, or about the costs of the services or items they planned to use it for. Given this context, therefore, most interviewees were either pleased with the amount of their budget or had no particular feelings about the level of their personal health budget either way. Some thought the budget was generous.

However, around a quarter of the interview sample were dissatisfied with the level of the budget because they anticipated being unable to purchase as much or as frequent services or treatments as they wished. A few were using their budget to pay for services that they had previously purchased privately; however the costs of these services had increased recently and so were not fully covered by the budget, which had already been set. One interviewee had

asked the local personal health budget lead officer whether his budget could be increased, but was told that there was *'no money'* for this. Those who were dissatisfied with their budget often assumed it was a *'blanket amount'* that had been calculated according to a standard formula for a particular condition or according to their historical use of NHS services. Neither of these alternatives was thought to reflect their actual needs.

Interviewees who were dissatisfied with the level of their personal health budget were asked whether they had thought about trying to change it. Some had complained and, in some cases, their budgets were being reviewed. However, others were unaware they could complain, even where their budget was too low to cover the level of services they would like to purchase. Others did not want to appear *'cheeky'* and were grateful for getting any help at all. Some people were aware that their personal health budget would be reviewed after a few months, which could include a review of its level against the costs of services.

Interviewees reported other concerns relating to the level of the personal health budget, including how underspends and overspends would be dealt with, or the period of time the budget was supposed to cover.

4.4 Summary

Interviewees reported a general lack of transparency in the level of their personal health budgets and the basis on which these had been calculated. A few people who had been offered a budget in response to a specific unmet need were unaware that they had a *personal* budget at all. Methods for calculating personal health budgets were thought to include assessed needs, historical use of NHS services or standard amounts for specific conditions.

In particular, there was no widespread evidence that interviewees knew the level of their budget in advance of starting to plan their support. Many interviewees also lacked any expectation of how much their budget should be. Consequently, many were satisfied with the level of their personal health budget, were unaware they could question the amount or were reluctant to do so. A minority, particularly those who had clear plans for using the budget and knew how much their desired services would cost, were less hesitant about questioning the budget level.

As in the previous section, one of the messages to draw out of this section is about the importance of prospective personal budget holders receiving detailed information about their budget, particularly the level of the budget and how this has been arrived at. Although some of the shortcomings reported here may reflect the early stages of the personal health budget pilots, many of

them could have been reduced or avoided through better information, advice and support.

5. Planning how to use the personal health budget

At the time of the interviews, around three months after being offered a personal health budget, not all interviewees had finally decided on how to use their budget but most had started to consider the options.

5.1 Experiences of care/support planning processes

Interviewees' accounts suggested wide variations across the pilot sites in the nature and formality of care/support planning processes. Reported experiences included completing detailed forms, discussions with healthcare professionals and written care/support plans. A small minority of interviewees were receiving help with care/support planning from specialist brokers.

Detailed discussions with healthcare professionals about needs, goals and preferences were reported to have been useful in generating ideas for using personal health budgets. Indeed, for some interviewees this was a rare opportunity to reflect on their health problems and support needs, and a positive contrast to the conversations they were accustomed to having with healthcare practitioners which were more tightly focused on clinical matters. Others appreciated being asked their opinion and offered choices.

However, care/support planning discussions could also be challenging and '*draining*', particularly for those with recent onset health conditions who had yet to find out what care or treatment might be helpful; some people were still getting used to thinking of themselves as a person with 'care needs'. Others did not recollect anything that approximated to a care/support planning 'process'⁷, and for some the process was additionally difficult without knowing how much their budget would be.

5.2 Deciding how to spend the personal health budget

Most people already had some ideas for using their personal health budget at the point of taking up the budget offer (Section 3). These included people offered budgets for NHS continuing healthcare, most of whom expected to

⁷ Some people had been provided with paperwork that detailed the amount of their personal health budget and how this would be spent. However, these were different kinds of documents to the more detailed 'care plans' which some people described or showed to the researchers.

use the budget to employ their own carers, and those who had been offered a personal health budget after they had highlighted a specific need or gap in provision. Most of this latter group had only considered using their budget for this specific item or service and had not thought beyond this; indeed, some were unaware that budgets could be used for other things. Others had no particular needs in mind prior to learning about personal health budgets, but had decided how they wanted to use the budget around the same time as deciding to accept the offer or after deciding to try a personal health budget.

Some pilot sites had provided lists of potential uses for personal health budgets, which were thought helpful by some people. Few interviewees had decided to spend their budget on items not included on these lists and some said this possibility had not even occurred to them. Interviewees in other pilot sites, who had not been offered a list of possible uses, had instead been encouraged to '*think outside the box*'. However, some of this latter group would have welcomed ideas, suggestions or lists of examples for permissible uses of the personal health budget. This need was particularly common where interviewees felt they had few unmet health-related needs, where their health problems were well-managed and had little impact on daily life. Other interviewees could not think what (else) they might usefully do to improve their health or were unable to undertake additional activities at the moment because of particularly poor health. Those who felt reluctant and uncertain about the new experience of having greater choice over their health services found reassurance and encouragement from key professionals, that the budget was legitimately theirs, helpful.

In describing their decision-making, many interviewees emphasised the wish to use their budget '*wisely*', in the '*right way*'. For some people, this meant ensuring that NHS resources were spent on items or services very closely related to health and wellbeing; for others, it meant making sure the budget had maximum benefit for their own needs and circumstances. For example, an interviewee who had purchased a piece of equipment shortly before receiving a personal health budget chose not to include this in his care/support plan but to focus the budget instead on his future health needs. Others planned to buy small items from their own private resources and to focus the care/support plan and personal health budget on more expensive items. Some interviewees had so far decided on using only part of the budget, either because they did not feel they needed anything more and did not want to spend the money for the sake of it, or because they didn't want to '*take advantage*' of or '*milk*' the scheme. People who had so far used only part of their budget knew the rest was available if and when they had further ideas about how to use it.

5.3 Uses of personal health budgets

Table 5.1 lists the items that interviewees had used, or were expecting to use, their budgets for. The most commonly mentioned uses were for carers/ personal assistants, physical exercise and alternative or complementary therapies.

Table 5.1 (Planned) uses of personal health budgets

| Type of use | Examples |
|--|--|
| Care | Employing carers or PAs |
| Physical healthcare treatments | Physiotherapy, speech therapy, podiatry, osteopathy, chiropractics |
| Healthcare or personal care equipment | Nebuliser, sanitary equipment |
| Psychological therapies and counselling | Cognitive Behavioural Therapy, Neurolinguistic Programming, coaching |
| Alternative or complementary therapies | Acupuncture, Reiki, massage, reflexology, aromatherapy, yoga, hydrotherapy |
| Cosmetic/beauty treatments | Manicure, hair removal |
| Physical exercise | Gym membership, exercise classes, home exercise equipment, personal training, exercise DVDs |
| Improved dietary management | Fresh fruit and vegetable delivery, dietetics sessions |
| Computers/technology | Laptop, mobile phone, electronic personal organiser, internet access |
| Aids and adaptations | Wheelchair, adjustable armchair, ramps, rails |
| Facilitating social activities and hobbies | Season ticket, craft materials, courses, musical instrument, driving lessons, family holiday, childcare |
| Domestic help | Gardener, cleaner |
| Domestic appliances | Fridge, freezer |
| Travel/transport | Travel to/from support groups, day centres, gyms |
| Administration fees | Personal health budget management/brokerage services, providers of employment admin support (taxation, National Insurance) |

Overall, it was more common for people to (plan to) use the personal health budget to buy new, additional services or items, or to fund items they were previously purchasing privately, than to buy alternatives to existing NHS care⁸. The main exception was where budgets-holders were able to switch from a previous care provider and employ their own carers/personal assistants instead; this was expected to improve the flexibility and tailoring of support to their individual circumstances (see Section 7). Some people were using their budget to purchase treatments or services for conditions other than their 'main' personal health budget condition.

Being able to purchase non-NHS or non-traditional healthcare was central to some interviewees' understanding of personal health budgets and a key factor in deciding to try a personal health budget (Section 3). In helping with care/support planning, healthcare professionals were also reported to have often suggested non-NHS services. A small minority had made a conscious decision not to use their budget for services like chiropody or counselling, that they believed should be widely available through the NHS. Conversely, others felt it would be '*cheeky*' or '*naughty*' to use their budget for items outside conventional healthcare, including alternative medicines.

5.4 Identifying and sourcing provision

Interviewees variously used the internet, visited shops or sought recommendations from friends and relatives to identify suitable sources of services or equipment. A number had pursued these investigations without help from health professionals, though several had been helped by family members. People who had taken on the task themselves were generally happy to do so, because they considered that they knew their own needs best. Those planning to use their personal health budget to employ carers sometimes already had someone in mind for the job.

Those who had been helped by health professionals to source items or services were pleased to have received their suggestions and have them take on the '*legwork*' of investigating suitable providers. Some who were planning to employ carers had welcomed help with advertising and recruitment or getting information about organisations that provided payroll help.

People who had been offered a personal health budget in response to a specific unmet need or area of dissatisfaction had no difficulty sourcing provision. Some already knew of local providers, having used these in the

⁸ 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.

past; others planned to use their budget to pay for something they were already buying with their own money.

5.5 Help, support and information in planning how to use the personal health budget

The different plans that interviewees had for using their personal health budgets were reflected in their different needs for support and information. Most of those commenting on the adequacy of the help they had received with planning how to use their budget said they had been well supported by the main personal health budget lead professionals, with additional support sometimes coming from family members or other health/social care professionals. Positive experiences of support were characterised by a good rapport with professionals who were well-informed, accessible and responsive.

Virtually all interviewees felt they had been sufficiently involved in deciding how to use their personal health budget. Even where suggestions had come from other people, the ultimate decision had been theirs alone and they felt their views and wishes had been respected. The only exception was one site where it appeared a decision had been taken to use personal health budgets to fund packages of NHS services for one patient group. However, there appeared to have been delays in communicating this to the budget holders concerned, who were unaware how their budget was being used until sometime later.

The amount of support that people felt they needed in planning the use of their budget varied. Some people had received relatively little support, but did not require much because they already knew exactly how they intended to use the budget. Interviewees felt less well supported where they found it difficult to get in touch with key professionals or felt that things had '*gone quiet*' in the care/support planning process. Some interviewees had had no recent contact with a key professional and were thinking about withdrawing from the pilot. A few people felt the planning process had been rushed, causing them to feel pressured in making quick decisions they were not entirely happy with.

Professionals had significant roles to play in making suggestions about possible uses for the budget, or helping the budget holder generate ideas. It seems that some healthcare professionals had given a much wider picture of the potential uses of personal health budgets than others. This was valued by interviewees who would otherwise have struggled to think of options, or where professionals had made suggestions that interviewees would not have thought of on their own: for example, interviewees had variously been

encouraged to think broadly about their needs; to use the budget to pursue hobbies; or think about how it could help family carers. On the other hand, some of those who were planning to use their budget to employ carers were not always told that other uses were possible⁹. Some acknowledged that they had been so focused on one particular use during the care/support planning process that they would perhaps not have been open to additional suggestions.

The most commonly noted gap in information was about the range of things personal health budgets could be spent on. Some interviewees would have found written lists of options – both general information and specific examples from people in similar situations – helpful: *'I think if there'd have just been [a] leaflet saying you could possibly use it for this, this and this, that would have been enough, I think'*. This was particularly the case where interviewees thought personal health budgets were for one specific purpose such as exercise or paying for care.

A few interviewees who had not known the amount of their personal health budget before completing their care/support plan would have found it helpful to know the amount of their budget before starting the care/support planning process. They had found it difficult to plan without this information and said they might have made different choices had they known the total budget. On the other hand, others felt that knowing the total budget could constrain full exploration of their needs in the early stages of care/support planning, as people would *'work to the budget'* and limit what they asked for, rather than think through the full range of everything that might help them.

Most of the interviewees who were planning to use the budget for exercise knew that their plans had been checked by a doctor or physiotherapist, or had had a physical assessment, to establish the activity would be safe. A few interviewees felt such 'risk assessments' were unnecessary and the delays involved could cause significant frustration.

5.6 Satisfaction with outcomes of care/support planning

The majority of interviewees were generally happy with their plans for spending their budget. However, a substantial minority had mixed feelings, either because not all of their needs had been met, or because they would have liked to use the budget for something else.

Among those interviewees who had originally thought they had no unmet needs for treatments or services and who had therefore struggled to come up

⁹ Some interviewees only became aware during the research interview that alternative uses of the personal health budget were possible.

with ideas, a few were ambivalent about the things they were going to try. Two interviewees had been unable to access the exercise classes they wanted to use their budgets for because of inconvenient location or timing. More commonly, a substantial minority of interviewees had had all or part of their care/support plan turned down by an assessment panel. Items that had been refused included mobility scooters, domestic heating costs, laptop computers, nutritional supplements, acupuncture, osteopathy, holidays and wheelchair maintenance. Interviewees' reports of why these had been declined were that they were insufficiently related to their health condition or that they exceeded the value of the personal health budget, which could not be 'topped up'.

Having (part of) a care/support plan turned down by an assessment panel caused interviewees disappointment; frustration if they felt that the panel had not understood the potential benefits of the treatment or activity; and anger at being unable to use '*their*' budget for things they thought important. One interviewee said his enthusiasm for the budget had '*waned*', while another was now confused about the purpose of personal health budgets.

As noted above (Section 4), most people were generally satisfied with the level of their budget. However, a few identified further things they would like to use the budget for had it been larger; these included additional items and more sessions of the care or therapy services they planned to purchase.

There were wide variations in the speed with which care/support plans were drawn up and approved and new services or items subsequently put in place. Some people had been pleased at how quickly they had begun to receive treatments or items had been delivered. Others described inexplicable lengthy waits, which could cause frustration. It was not clear how far these delays reflected the very early stages of the pilots in PCTs that had still to establish arrangements for releasing funding, or were associated with particular types of items contained in care/support plans.

5.7 Summary

Most people already had some ideas about how they would use their personal health budget at the point of taking it up. Some of these ideas were very specific and these interviewees often failed to consider alternative or additional uses. Other interviewees found it harder to come up with ideas, sometimes because they felt they had low levels of need or lacked knowledge about what else might help their health condition. On the other hand, those who took up the personal health budget offer with very specific uses in mind were not always encouraged to think more broadly about alternative or additional uses.

Many people had been able and willing to investigate and source provision without help; others had appreciated the advice and help of key professionals in looking into sources of provision on their behalf.

Many interviewees felt that they had all the information they needed to plan the use of their budget, but several felt that more information on the range of possible or permissible uses would have been helpful and some would have liked to have known the amount of their budget at an earlier stage. Similarly, there were mixed views on the adequacy of the support received in planning how to use the personal health budget. However, there were significant variations between interviewees in the levels of information and support that they felt they needed.

Generally, interviewees felt they had been sufficiently involved in planning the use of their personal health budget. Most had been able to find the things on which they wanted to spend their budget. However, some people had had (part of) their plan turned down without knowing exactly why. Interviewees were also generally satisfied with the level of their personal health budget, but some could think of other things they would like to purchase had the budget been bigger.

6. Management of the personal health budget

This section considers interviewees' views on the deployment options for personal health budgets and the choices they made. For those who also had a personal budget for social care, we also consider whether and how the two budgets were integrated.

6.1 Choosing how to manage the personal health budget

Not all interviewees had made arrangements for managing their personal health budget at the time of the interview. Among those who had, perceptions of the options and the reasons for choosing a particular option varied widely.

Only around a quarter of interviewees recalled being offered a choice of deployment options. Those who chose PCT or third party arrangements did so because they had experience of this working well for a social care personal budget; because it avoided opening and managing a separate bank account; because it avoided the 'hassle' of collecting receipts for services and treatments; and because it avoided any temptation to misuse the money. Others given a choice had opted for direct payments because it suited their current lifestyle; they enjoyed the associated administrative work; they had previous experience of social care direct payments; they anticipated enjoying

greater choice and flexibility over how the budget was used; or they wished to avoid charges levied by third party agencies for managing budgets. A few interviewees had opted for direct payments but then used a company to manage the payroll for their paid carers; one pointed out that the stress of implementing a new care regime was enough to deal with without also having to administer staff wages.

In contrast, most of those interviewees who were far enough into the care/support planning process for deployment options to have been raised could not recall being asked how they would like their budget to be managed. Sometimes this lack of recall was attributed to health problems. Some of this group reported being told their budget would be managed by a third party, others that it would be held by the PCT personal health budget team. Some had simply been told that a direct payment was not possible for them.¹⁰

Some of those who reported being told their budget would be managed by the PCT or a third party were content with this because it meant the budget was less likely to be misused; they felt uncomfortable having NHS money in their bank account; or they thought managing a budget would be stressful. However, others thought they should have been trusted with a direct payment and that third party management risked unnecessary delays in items being ordered and delivered. One person likened third party management to being '*held over a barrel*' with regard to contacting and paying suppliers, while another felt guided towards a particular deployment option.

Others who could not recall being offered a choice of deployment options had been told they would receive their budget as a direct payment for which they would need a separate bank account. Details of the direct payment option were not always clearly explained – would the budget for the whole year be paid to them all at once, for example? Some of these interviewees thought that, given a choice, they might have preferred third party management in order to avoid the stress and responsibility of direct payments. Others thought it had probably been '*assumed*' they would want a direct payment, especially when the personal health budget was for NHS continuing healthcare and followed on from a social care direct payment.

Of the interviewees who commented on the help they had been given in choosing how to manage their personal health budget, most felt well supported (in some cases very well), with relevant information. The most common gaps in information concerned setting up special bank accounts and paying staff wages through direct payments; one interviewee questioned how

¹⁰ There is currently flexibility in what deployment options pilot sites offer. In particular, not all of the pilot sites are authorised to offer direct payments, though the option of applying for this power is open to all of them.

'Mr or Mrs Average' was meant to be able to cope with this level of administration.

6.2 Personal budgets for social care and health

Several interviewees already had personal budgets for social care; these were used to pay for personal care, to employ carers or to fund social activities. These interviewees anticipated having to have separate bank accounts for the two budgets, or having them both managed separately by a private company. A few other interviewees with complex needs were receiving support funded jointly by the NHS and local authorities and they were uncertain how their personal health budget would be integrated with these existing arrangements.¹¹

6.3 Summary

A quarter of interviewees recalled being offered a choice of how their personal health budget would be managed. Others could not recall being offered any such choice, and not all were happy with the direct payment or third party management arrangements that had apparently been chosen for them. Whether or not they recalled being offered a choice, interviewees gave similar reasons for preferring third party and direct payment options respectively. The most common gaps in information related to the details of managing direct payments, particularly setting up bank accounts and payroll management for employed carers.

At this early stage in the pilots, there was little evidence of personal health budgets being well integrated with social care personal budgets.

7. Anticipated and early outcomes of personal health budgets

This section looks at interviewees' experiences and expectations of the early outcomes from their personal health budgets.

¹¹ The legislation requires that money must be paid into a separate bank account from those the individual already holds. There is, however, flexibility for a personal health budget direct payment and a social care direct payment to be paid into the same account.

7.1 Early outcomes of personal health budgets

Although it was very early in the pilot projects, some interviewees were already able to report experiencing greater choice and control over their care, who provided it (including the opportunity to access non-NHS services or alternative therapies) and when. In some instances, this had already led to direct health gains. For example, new, more efficient equipment such as a nebuliser, or new treatments like acupuncture, were already leading to improvements in health and wellbeing. Others reported improvements to their overall quality of life, for example, by having a new wheelchair that enabled them to get out more or being able to employ specialist staff to provide care. One interviewee anticipated the increased independence created through the personal health budget would help him move towards obtaining paid work. Others anticipated being able to access a wider range of services or improvements in their motivation and morale. Personal health budgets were also expected to bring benefits for some relatives, by enabling more flexible paid care to be purchased and reducing heavy reliance on family care-givers.

In a few instances, personal health budgets had allowed interviewees to access services and facilities, such as gym membership, that they had previously been unable to afford or had been purchasing privately.

Indirect effects on interviewees' health were also reported, for example because the assessment and care/support planning processes had prompted medication reviews or had simply provided opportunities for in-depth discussion of their health and support needs with a practitioner.

Only two interviewees reported problems that reduced these benefits. One was still paying for some treatments privately because the budget was insufficient to cover all they had asked for in their care/support plan and they wanted to maintain the level of treatment they had been accessing previously. The other reported long delays by the third party organisation managing her budget in ordering equipment and reimbursing her for items she had bought privately. A few others also anticipated reduced benefits if their budget turned out not to cover all the treatments or services they needed.

7.2 Personal health budgets and personalisation

Interviewees were asked if they thought the personal health budget had the potential to 'personalise' health treatments or services to their individual situations. Only a few interviewees were already familiar with and fully able to engage with this concept. A few people had difficulty thinking about healthcare in terms of personalisation and said that they were used to a professional telling them what would be best for them. However, most

interviewees anticipated that the greater choice and flexibility allowed by personal health budgets would allow access to more individualised help, including items not normally available through the NHS - for example, non-traditional items like a laptop computer or gym equipment for use at home. Some people liked being able to obtain voluntary, community or private sector services as an adjunct to NHS mental health services, which they felt had taken them as far as possible. Others appreciated being able to arrange care services that were (more) suitable for them, or deciding who provided their care and when to fit better with their lifestyles – for example, being able to participate in wider social activities rather than attending a day centre. One interviewee reported that the care now in place through his personal health budget had enabled him to go from ‘*existing*’ to ‘*living again*’.

Personal health budgets also allowed interviewees to manage aspects of their condition which had previously been neglected: one interviewee planned to buy a satnav system to reduce her anxiety about going out, for example.

Some interviewees did not expect any differences in the services they received as a result of having a personal health budget. Rather, the personal health budget simply replaced another source of funding (for example, social care or private funding) for these services. The (anticipated) benefits were therefore less dramatic, although they still enabled personalised care regimes to be maintained. Others were not yet sure that the level of their budget would cover all their needs, so were unable to anticipate clear benefits.

7.3 Anticipated difficulties with personal health budgets

A minority of interviewees could not foresee any difficulties arising with their personal health budget. However, among the majority there were some anxieties. A number of interviewees whose budgets were being managed by a third party had already experienced delays in the delivery of equipment or services and had anxieties about this in the future. Others were anxious about being able to find appropriate sources of care; about their desired care/support plan being turned down; or about managing their budget - would they keep receipts correctly or manage their payroll responsibilities, for example?

A number of people were anxious whether the level of their personal health budget would be enough to fund all the treatment or services they needed, particularly if their needs increased in the future.¹² One described this as ‘*a major worry*’. This anxiety was partially mitigated for some people, who understood that they could pull out of the pilot if it turned out not to work for them.

¹² However, a review of the care/support plan or of the budget itself can be triggered by the PCT or the budget holder.

7.4 Summary

Most interviewees had already experienced or anticipated positive outcomes, including better services and treatments; others thought that the personal health budget would allow them greater choice, control and flexibility over services. Some people also felt that their financial position would improve, where they could substitute a personal health budget for their own funding where this was previously used to purchase goods and services. Personal health budgets were considered by some to have increased the degree of personalisation, particularly by enabling access to private services and goods and being able to arrange more suitable and timely services.

For a minority of interviewees, early or anticipated outcomes were more mixed. Some had experienced delays in the delivery of equipment and others were anxious about whether their budget would be sufficient to meet their needs.

8. Conclusions

This section draws some conclusions from the interviews with a sub-sample of personal health budget holders, around three months after the offer of a budget. Some of these conclusions undoubtedly reflect the early stages of the personal health budget pilots and the pressures that pilot sites were under at this point to recruit people to the evaluation and offer personal health budgets. The experiences reported here therefore cannot be assumed to be representative of those subsequently offered personal health budgets in the pilots, nor of those involved in any wider rollout of the initiative beyond the pilot stage. However, they do provide valuable information on what appears to work well or less well, from budget holders' perspectives, and therefore offer potential learning for future service development.

Although the interviews did not collect systematic data on interviewees' health problems, the severity and complexity of their conditions varied enormously. This diversity is reflected in the range of experiences reported here. It suggests that personal health budget assessments, support for care/support planning and criteria for approving how budgets are used all need to adopt holistic perspectives towards health and wellbeing, rather than focusing only on a single condition.

The sample also reflected the range of circumstances in which interviewees had been told about and offered personal health budgets. Those offered a budget in response to a specific unmet need tended to see the budget simply

as a way of meeting that need and had little concept of, or interest in, the wider aims of the pilots. Interviewees who had previously had social care personal budgets were more familiar with the policy aims of personalisation, choice and control and already had experience of employing their own carers. For these interviewees, personal health budgets enabled them to maintain or extend their existing personalised care arrangements.

A third group had been offered a personal health budget shortly after a major trauma such as a stroke. Here, identifying unmet needs was particularly difficult because of the sudden recent change in health status, which could also change yet further during the course of rehabilitation.

A fourth group of interviewees had stable, well-managed conditions and some of these found it hard to identify any unmet needs. For them, a personal health budget offered the opportunity to supplement their existing healthcare with more preventive interventions. The next round of interviews will explore how far these had contributed to improving interviewees' health and wellbeing and reduced their use of other treatments¹³.

Overall, there appeared to be few major anxieties or obstacles to trying a personal health budget¹⁴. Interviewees understood they were being offered additional support (albeit in an unconventional way for the NHS), including the opportunity to obtain independent sector goods and services. To the extent that there appeared to be no implications for other healthcare treatments they were receiving, most could foresee no major risks.

Variations in the amount of information that interviewees had received before deciding to try a personal health budget and subsequently in deciding how to use that resource were striking. These variations may partly reflect the early stages of the personal health budget pilots at which interviewees were selected. However, the interviews demonstrate that some people may need more information than others; both general and personalised information in different media/formats is also required. Interviewees' accounts suggest that information-giving and decision-making about personal health budgets needs to be conceptualised as an ongoing process, rather than a one-off event, as new questions and uncertainties can arise during and after the assessment and care/support planning processes.

¹³ The final report of the evaluation will include an analysis of the overall costs and benefits of the personal health budget pilot programme.

¹⁴ Again it should be noted that interviewees had all accepted the offer of a personal health budget. Possible obstacles would need to be explored with people who have refused this offer.

Similarly, some people require substantial support in planning how to use their budget and in identifying suitable services or goods, particularly if they perceive themselves to have no unmet healthcare needs, or have recently experienced the sudden onset of a serious health problem. Those who early on identify a specific use for a personal health budget may also need encouragement to think more widely about other options.

Examples of items that personal health budgets could be used for would be helpful, particularly for people who have difficulty identifying a potential use for their budget or are uncertain about the range of legitimate uses. Clarity on the part of key health professionals about appropriate uses for personal health budgets is also essential. Interviewees who had what they considered appropriate uses for their budget turned down risked becoming resentful and disillusioned with the pilot.

Few interviewees appeared to know the level of their budget before they began planning how to use it. This diverges fundamentally from the principles underpinning personal health budgets. Ignorance of the level of the budget meant that care/support plans risked being based on incorrect assumptions; a few interviewees would have made different choices, had they known the level of the budget at the time they planned its use. One clear finding from these interviews, therefore, is that clear information about the level of the budget, and the period it is intended to cover, is essential at the start of the care/support planning process.

Better information is also needed on the management options for personal health budgets; fewer people had been offered an informed choice about this than would have liked one. Details of the direct payment option in particular are needed, both during and after the care/support planning process, as some questions about managing direct payments may only arise once the personal health budget is in payment. As personal health budgets become more widespread, clarity about their interface with social care personal budgets will also become important. Delays in ordering, delivering and paying for items need to be resolved, although these may reflect the early stages of the personal health budget pilots.

The diversity of the sample was further reflected in their varying understandings of key policy concepts like choice, control and personalisation. Overall, the extent to which personal health budgets actually offer new opportunities for personalisation, choice and control depends crucially on the information that potential budget holders receive about the aims of personal health budgets and on the support they are given to think holistically about how their health and wellbeing could be improved.

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Appendix A Research methods and sample

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 first round of interviews with budget holders, approximately three months after taking up the offer of a personal health budget.

A.2 Target sample

The study aimed to interview a sample of 55 personal health budget holders. The timing of the three month interview was intended to allow for reflection on the decision-making and care/support planning process at a point in time when participant recall remained relatively good but sufficient time had elapsed for some care/support planning to have taken place.¹⁵

Six health conditions would be 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 receiving NHS continuing healthcare. Target recruitment numbers for each condition were agreed in advance, as detailed in Table A.1.

¹⁵ Previous experience of the Individual Budgets Pilot evaluation suggested that scheduling interviews any earlier than three months may mean that little planning had taken place with the budget holder.

Table A.1 Recruitment targets: budget holder interviews

| Health condition | Recruitment target |
|---------------------------|--------------------|
| COPD | 5 |
| Diabetes | 5 |
| Stroke | 10 |
| Mental health | 10 |
| NHS continuing healthcare | 10 |
| LTNC | 15 |
| TOTAL | 55 |

A.3 Ethical considerations

The wider evaluation received ethical approval from an NHS Research Ethics Committee; no additional approvals were required for the in-depth strand. However, in accordance with good practice, separate information sheets and consent forms specific to the in-depth research strand were prepared for participants. A number of preparatory measures (detailed below) were also carried out, in order to ensure appropriate and sensitive conduct of the in-depth interview research.

A.4 Constructing the sample

The sampling frame was provided by the wider personal health budget evaluation. The research team at the University of Kent supplied the SPRU research team with a database of all individuals recruited to the personal health budget evaluation. Transfer of the database was done electronically via a secure virtual private network. This database was updated periodically, allowing the SPRU team to construct a sample iteratively, according to the recruitment targets for each health condition and also balanced for other characteristics including age and gender. The primary sampling criterion was the individual's health condition; secondary criteria were a spread of ages and an approximately even gender balance. The intention was also to include a range of ethnic groups within the in-depth sub-sample. However, this was dependent on the wider sample and, given the small numbers of non-White British budget holders in the evaluation at the time that people were being approached for the interviews, the potential number of minority ethnic interviewees in the in-depth sample was similarly limited.

The researchers aimed to include participants from at least half of the 20 in-depth evaluation sites in order to obtain a variety of local experiences. The range of health conditions being covered in the different pilot sites also guided sampling decisions. Most sites were offering personal health budgets to only two or three condition groups and their overall recruitment targets also varied, meaning that some sites offered more potential for in-depth sample selection than others.

Regarding deployment options for personal health budgets, the intention was to include some budget holders who were receiving direct payments. However, this would again be dictated by the number of pilot sites offering direct payments at the time of fieldwork and the numbers of budget holders taking up this deployment option.

A.5 Preparing for recruitment and interviewing

Prior to beginning fieldwork, the two researchers conducting the in-depth interviews held an informal meeting with a small group of colleagues in SPRU who had substantial collective experience of interviewing people with long-term and severe health conditions. This meeting highlighted a number of practical and ethical considerations to take into account when arranging and conducting the interviews. These included, for example, the most appropriate times of day to interview people with fluctuating conditions or complex medication regimes; the importance of pacing and breaks for participants who could tire easily; how to respond if a participant became unwell or distressed; and appropriate ways to involve other parties who might wish to be present during interviews.

A key source of background information in preparing for the semi-structured interviews was the personal health budget lead in each of the 20 in-depth pilot sites. When details of budget holders were provided to the SPRU team by the University of Kent, the SPRU researchers contacted the personal health budget lead in each site to gather up-to-date information on the personal, health and wider circumstances of each budget holder who was being considered for recruitment to the semi-structured interview sub-sample. The purpose of these preliminary enquiries was to avoid making approaches to budget holders if their current circumstances suggested this would be inconvenient or inappropriate and to ensure that the researchers were aware of any potential risks to their own wellbeing posed by that budget holder's circumstances.

The researchers first sent an introductory email to personal health budget leads explaining the reason for their contact, and then made a telephone call to gather key information including:

- The main health condition for which the person was receiving a personal health budget.
- Any recent changes in health or personal circumstances that should be taken into account before making contact or making a home visit.
- Any language or communication needs that should be taken into account when making initial contact and carrying out a research interview.

Personal health budget leads and care navigators were invariably very helpful in responding to these requests for information. Sometimes personal health budget leads identified some budget holders as particularly ‘good’ people to approach. However, the researchers attempted to set aside this type of information so as not to construct a sample biased towards the most articulate, positive or amenable respondents. Personal health budget leads and care navigators also commented on the likelihood of the budget holder being capable of engaging in an in-depth interview of the type intended for this strand of the evaluation. On the basis of the above range of information, the researchers made decisions about who to approach with an invitation to take part in an in-depth interview.

A.6 Recruitment and consent

Having identified potential participants, recruitment proceeded with an initial invitation letter and information sheet sent to selected budget holders. All budget holders had been informed when recruited to the wider evaluation that they may be contacted about taking part in some more in-depth research. However, being aware that not all participants would recall this clearly, the invitation letter reiterated why participants were being contacted and the information sheet set out comprehensive details of what participation in the in-depth strand of the study would involve.

Invitation letters were sent out in several successive waves, to correspond to the three-month point for budget holders, to pace the fieldwork, and also because of the initially slow recruitment to the wider evaluation sample. Experience of the Individual Budgets Pilot evaluation also suggested that it would be worth reserving some interviews for later on in the pilots, when personal health budgets pilot sites’ recruitment and care/support planning processes had ‘bedded in’.

In the first wave of invitation letters, the researchers offered a two-week opt-out period, during which budget holders could state (by pre-paid postal reply slip, telephone or email) if they did not wish for further contact from the researchers. The first six invitation letters sent out included this option, but no opt-outs were received during the two-week period. Following the two-week

opt-out period, the researchers contacted budget holders by telephone to ask if they had any further questions and to see if they would be willing to participate in a research interview. Of these initial six approaches, four participants agreed to interview, one opted out at the point of telephone contact and one was uncontactable by telephone. Of those who agreed to be interviewed, most did not have a clear recall of the invitation letter by the time of the researcher's telephone call, though they still expressed willingness to take part in an in-depth interview. Based on this experience, the research team decided that a two-week opt-out period was unnecessary and invitation letters were amended to say that a researcher would be in touch by telephone in a few days' time to talk about possible participation.

Budget holders who chose not to take part in an in-depth interview did so because of severe ill health, current personal circumstances (for example, moving house), too many other time commitments, or simply feeling that it would be too demanding. In a number of cases where the budget holder was very unwell, frail or had communication difficulties, the initial telephone conversation took place with a third party (typically a partner) and in such cases, it was usually established that it would be inappropriate to conduct an in-depth interview with the budget holder. Wherever possible, however, the researchers endeavoured to speak to the budget holder themselves before deciding not to pursue an interview.

A.7 Achieved sample

Table A.2 shows the characteristics of the achieved sample whose three month interviews are included in this report.

Table A.2 Characteristics of achieved sample

| Number in study group | 58 |
|-----------------------|----|
| Age* range | |
| Teens | 1 |
| 20s | 8 |
| 30s | 11 |
| 40s | 7 |
| 50s | 10 |
| 60s | 13 |
| 70s | 4 |
| 80s | 3 |
| Gender | |
| Female | 31 |
| Male | 27 |
| Condition | |
| COPD | 7 |
| Diabetes | 6 |
| LTNC | 13 |
| MH | 9 |
| NHS CC | 15 |
| Stroke | 8 |

* 1 person's age unknown.

A.8 Conducting the interviews

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:

- Health condition and satisfaction with services prior to taking up a personal health budget.
- Finding out about personal health budgets.
- Making the decision to try a personal health budget.
- The amount of the personal health budget and feelings about this.
- Deciding how to use the personal health budget.

- How the personal health budget is managed.
- Experiences so far of having a personal health budget.

Interviews typically lasted 80-90 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.

Although the researchers tried to avoid conducting interviews with 'proxy' respondents on behalf of a personal health budget holder, in a number of cases a third party was present during the interview and often contributed a substantial amount to the conversation.

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.9 Data analysis

The completed interviews were transcribed in full. Data (summaries and quotations) was 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.