in Control

LANCASTER UNIVERSITY

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PERSONAL HEALTH BUDGET HOLDERS AND FAMILY CARERS

THE POET SURVEYS 2015

POET™
Personal Outcomes Evaluation Tool

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AUTHORS: Chris Hatton, Centre for Disability Research at Lancaster University and John Waters, In Control

Personal health budgets are an allocated sum of money to help people meet their identified health and wellbeing needs, as planned and agreed between the person and their local NHS team.

The aim is to give people greater choice and control over the healthcare and the support they receive. People in receipt of a personal health budget work with their local NHS team to develop a care plan that describes:

- Their individual health needs
- The health outcomes they want to achieve
- The amount of money in the budget
- How the budget is going to be spent.

1 INTRODUCTION

Over recent years the NHS in England has started to change the way in which some important decisions are made about how it uses resources. An increasing number of people with health care needs are being offered the opportunity to take control of their own personal health budget, and by doing so are being invited to take a much greater role in decisions about their health care.

Personal health budgets are intended to reshape the relationship between people with health care needs and the professionals they look to for help. The goal is for personal health budgets to create a more equal partnership between clinician and patient, one where the person is fully informed and takes an active role in their own care, support and treatment.

Personal health budgets represent a powerful shift in the way the NHS allocates and uses its resources. Rather than adopting a passive role, individuals in receipt of a personal health budget work in partnership with an NHS team member to develop their own personal care plan. The plan sets out their assessed needs, the health outcomes they want to achieve, the amount of money in the budget and how the money is going to be spent.

The intention is that individuals can use a personal health budget to pay for a wide range of items and services, potentially including therapies, personal care and equipment, allowing more choice and control over the health services and care provided, ultimately leading to better outcomes for the individual.

The Government is committed to rolling out personal health budgets across the NHS in England and since October 2014 adults eligible for NHS Continuing Healthcare and children in receipt of continuing care have had the right to have a personal health budget. The ambition is clear, that personal health budgets should be introduced beyond NHS Continuing Healthcare. *The Forward View into action: Planning for 2015/16*[1] sets an expectation that CCGs will lead a

1 *www.england.nhs.uk/ourwork/forward-view/*

"major expansion in 2015/16 in the offer and delivery of personal health budgets to people, where evidence indicates they could benefit". CCGs should include clear plans for expanding personal health budgets in their local Joint Health and Wellbeing Strategy. NHS England continues to support CCGs, through a dedicated delivery programme, which includes support to help CCGs develop their own local offers.

Last summer Simon Stevens, the Chief Executive of NHS England announced the Integrated Personal Commissioning (IPC) programme, aimed at improving the quality of life of people with complex needs, enabling them to achieve outcomes that matter to them and preventing crises in people's lives that lead to unplanned hospital admissions or institutional care. Nine demonstrator sites have been selected to explore how an individual's health and social care funding can be brought together, and how person-centred care planning can give people more control over how this money is used, including personal budgets. This will enable more people to have personal health budgets or integrated personal budgets which span health and social care.

Both personal health budgets and the new Integrated Personal Commissioning programme aim to improve the quality of people's lives and their experience of the services they receive. As the number of people with budgets increases it will be important to learn from the experiences of people taking them up. The personal outcomes evaluation tool, (POET) described in this report, provides a helpful and practical way of doing this. The tool has been made available to all CCGs throughout 2014-15 and this report provides important learning on people's experiences during this period.

The introduction of personal health budgets to the NHS represents a potentially powerful innovation, as they allow individual patients the opportunity to control resources previously managed by professional commissioners. The intention is to improve individual choice and control and to ensure patients receive support and services that are tailored to their own individual needs and circumstances. This more personalised approach is ultimately intended to be more cost effective and lead to better outcomes. It is therefore essential to understand both the cost of providing personal health budgets and the outcomes achieved by people in receipt of them, in terms of their health and wellbeing and in relation to their day to day life.

THE POET SURVEYS

The POET tools used in these surveys were aimed at two key groups affected by personal health budgets. People with health needs who had been allocated a personal health budget and the family member caring for individuals in receipt of personal health budgets. Different versions of the tool were used for each group. Both versions asked people questions in the same broad areas; why they or the person they cared for needed support, what the process of taking control of a personal health budget was like and how the personal health budget made a difference to aspects of their lives.

Some of the process questions in the survey were designed to determine how well the policy aspirations of personal health budgets were being implemented. To what extent the ambition of people being more actively involved in the development of their own care plan was becoming a reality. Other process questions explored whether aspects of the personal health budget process (such as, who helped people plan, whether people felt their views had been included in the planning, and how the budget was held) were associated with better outcomes.

Personal health budgets are still at an early stage of implementation. There is no published data collection; NHS England estimates that around 4,000 people had a personal health budget in March 2015, which would mean that around 7% of current budget holders took part in the POET survey.

POET is a self-reported user experience survey tool, which is intended to be used at the time that the personal health budget is reviewed. This is normally 3 months after the budget is in place, and then at least annually. The people who respond are self-selected, so may not be representative of all personal health budget holders.

2 MAJOR FINDINGS

The POET survey does not measure health outcomes. Its purpose is to provide insight into the experience of personal health budget holders and their families, and the impact that having control over the budget has on their lives. The sample for the survey is fairly small so the findings need to be interpreted with caution.

- Over 85% of personal health budget holders reported their views had been included developing their support plan.
- The most common way to use a personal health budget was on care and support services (60%), followed by personal assistants (48%), community and leisure services (27%), and equipment (25%).
- Over 80% of personal health budget holders reported their budget having a positive impact on their quality of life (85%), independence (81%), and arranging support (84%).
- Over 70% of personal health budget holders reported their budget having a positive impact on their self-esteem (76%), feeling safe (76%), control over life (74%), family relationships (71%)and dignity (78%).
- Small numbers of people (under 5%) reported their personal health budget as having a negative impact on any the 15 aspects we asked about.
- People who felt their views were fully included at key parts of the personal budget process (needs assessment, support planning, budget setting) were significantly more likely to report a positive impact of their budget.
- People who found different aspects of the personal health budget process was easy were more likely to report good outcomes.
- Around 15% of personal health budget holders said that some aspects of the process were difficult for them.
- Over 75% of carers said that having a personal health budget had a positive impact on day to day stress (82%), their ability to continue caring (92%), the quality of life for the carer (87%), quality of life for the person (91%), and choice and control for the carer (76%).
- Less than 3% of carers reported any areas of their lives getting worse as a result of personal health budgets.

3 THE POET PERSONAL HEALTH BUDGETS SURVEY

This report presents the findings of the POET surveys of personal health budget holders and carers, including:

- A brief description of the surveys and how we collected the information.
- Findings of the POET survey of personal health budget holders in England, including:
  - Who responded to the POET survey
  - How personal health budgets are being managed and how people are supported in using them
  - What difference personal health budgets make or don't make to people's lives
  - What factors are associated with better outcomes for personal health budget holders.
- Findings of the POET survey of carers of personal health budget holders in England, including:
  - Who responded to the POET survey
  - The circumstances of carers and the personal health budgets used by the people they are supporting
  - What difference personal health budgets make or don't make to carers' lives
  - What factors are associated with better outcomes for carers.

The POET Surveys

This section briefly describes the content of the POET surveys for personal health budget holders and carers, and how people completed the questionnaires.

THE POET SURVEYS OF PERSONAL HEALTH BUDGET HOLDERS

The POET survey for personal health budget covered the following areas:

- Information about the personal health budget (which organisation provides it, how long the person has held the budget, previous local authority support, how the budget is managed, the amount of the budget).
- Information about personal health budget support planning.
- Information about how easy personal health budget holders found nine aspects of the personal health budget process.
- Information about whether the personal health budget has made a difference (either positive or negative) across 15 aspects of the person's life.

- Information on people's self-rated assessment of their current general health.
- Information about the extent to which personal health budget holders felt their views had been included in various aspects of the process.
- Equalities monitoring questions (gender, age, disability, ethnicity, religion, sexual orientation).
- Space for people to write in their opinions on personal budgets.

THE SURVEY FOR CARERS OF PERSONAL HEALTH BUDGET HOLDERS

The POET survey for carers contained the following questions:

- Information about who carers are caring for and how much care they provide.
- Information about the personal health budget held by the personal budget holder.

The extent to which carers felt their views were included in various aspects of the process.

- Information about whether the personal health budget holder's budget has made a difference (either positive or negative) across 8 aspects of the carer's life.
- Information on carers' self-rated assessment of their current general health.
- Equalities monitoring questions (gender, age, disability, ethnicity, religion, sexual orientation).
- Space for people to write in their opinions on personal budgets.

People who found the process easy were more likely to report positive outcomes.

4 RESEARCH ETHICS

Because the POET surveys were designed for people to evaluate their experiences of existing personal health budgets, the surveys were service evaluation rather than research according to guidance from the National Research Ethics Service,[2] and therefore did not require Research Ethics Committee approval.

All formats of both POET surveys explained how the information would be used. Anonymity and individual confidentiality were guaranteed – we did not ask for people's names. Before completing the survey everyone was asked to indicate if they agreed for their information to be used in reports such as this one before they completed the survey.

In total, 302 personal health budget holders and 247 carers completed the POET survey and gave their agreement for the information to be used. Personal health budget holders identified 31 different NHS organisations as providing their personal health budget. 217 personal health budget holders said their budget had been allocated to them by the NHS, 28 by their local council, 33 by both, 22 did not know. Carers identified 37 different NHS organisations as providing their personal health budget. 189 carers said their budget had been allocated to the person they care for by the NHS, 15 by their local council, 30 by both, 10 did not know.

In both personal health budget holder and carer versions, responses to all the POET survey questions except questions inviting open text responses were recorded numerically and converted into excel and a statistical software package, SPSS, to allow us to statistically analyse the responses.

All between-group differences and associations were conducted using the appropriate non-parametric test, with the statistical significance level set at $p<0.05$ (i.e. the odds of the result occurring by chance was less than 1 in 20). Throughout this report, where we refer to a difference between groups or a significant association between factors, this is underpinned by a non-parametric statistical test with $p<0.05$.

2 National Research Ethics Service (2013). Defining research. London: Health Research Authority. www.hra.nhs.uk/documents/2013/09/defining-research.pdf

Over three quarters of carers said that having a personal health budget had made things better for the person they care for.

For the open questions people were asked what they felt had worked well, what had not worked well and what they would change. We used a complete list of what people wrote to develop a set of themes summarising people's experiences from what they had written in response to each question. This was done separately for personal health budget holders and carers.

302 personal health budget holders from 31 different NHS organisations and 247 carers from 37 different NHS organisations completed the POET Survey.

5 FINDINGS: PERSONAL HEALTH BUDGET HOLDERS

This section of the report presents findings for personal health budget holders responding to the POET survey, including:

- Who responded to the POET survey?
- What personal health budgets people are using and how people are supported in using them?
- What difference personal health budgets make to people's lives?
- What factors are associated with better outcomes for personal health budget holders?

Who responded to the POET survey?

As mentioned earlier, a total of 302 personal health budget holders completed the POET survey and gave their agreement for the information to be used. As people could choose not to complete particular questions within the survey, percentages are of the total responding to that particular question. In some areas respondents were asked to indicate if a particular question was not relevant to them. Equalities monitoring information is presented in detail in Appendix 1.

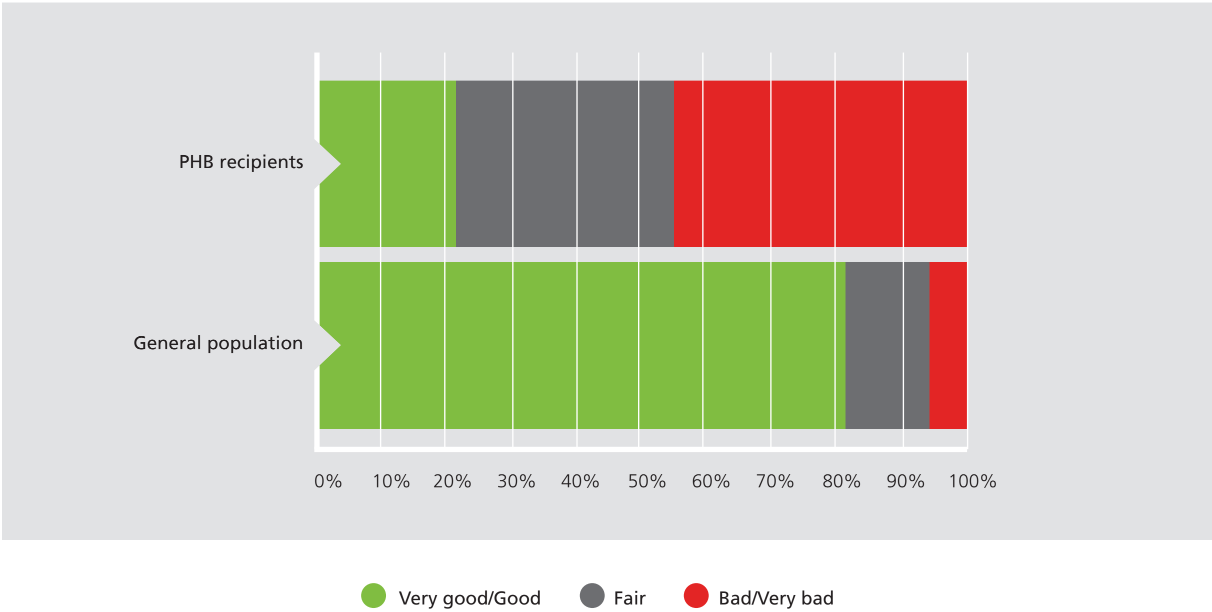
- Just over a third of personal health budget holders (37.6%) answered the POET survey on their own, nearly a third (30.7%) of people said they had some help from another person to complete the survey, a small number completed the survey in a meeting or interview (7.2%), and nearly a quarter of the surveys returned were completed by someone else on behalf of the personal budget holder (24.5%).
- Respondents were equally divided by gender – half of respondents (48.1%) were men.
- In terms of age, just over a third (36.1%) of personal health budget holders were aged 16-44 years, just over a third (36.4%) aged 45-64 years, and just over a quarter (27.5%) were aged 65 years or over.
- A majority of respondents were White (89.2%), with a minority of people from other ethnic groups (10.8%).
- Over half of respondents were Christian (62.5%), over a quarter (28.1%) of respondents reporting themselves to have no religion.
- A majority of respondents reported themselves to be heterosexual/straight (85.3%).

The POET survey for personal health budget holders also asked people to state the main reason for which they were getting a personal health budget. A third said they had complex health needs (33.9%) or a physical disability (32.2%). Other responses included people stating the main reason for them getting a personal health budget was mental health difficulties (10.2%), substance misuse (4.0%), learning disability (4.0%), being an older person (2.7%) or another reason (12.8%).

Because of the limited number of responses to the survey it was not possible to conduct analyses of the data comparing across these different groups, as that would be difficult to interpret with any confidence.

Finally, we asked the same question used in the 2011 Census concerning people's self-rated general health in the last 12 months. As Figure 1 shows, the personal budget holders responding to the POET survey reported their health as much poorer than the general population in England.[3] Less than a quarter (21.5%) of personal health budget holders reported their health as good or very good, compared to over three-quarters (81.4%) of the general population, and approaching a half (45.1%) of personal health budget holders reported their health as bad or very bad compared to 5.4% of the general population.

FIGURE 1: Self-reported general health of personal health budget holders vs the general population of England (Census 2011)



3 *Office for National Statistics (2013). General health in England and Wales, 2011 and comparison with 2011. www.ons.gov.uk/ons/rel/census/2011-census/key-statistics-and-quick-statistics-for-wards-and-output-areas-in-england-and-wales/rpt-general-health-short-story.html#tab-General-health-across-the-English-regions-and-Wales*

How are people holding personal health budgets?

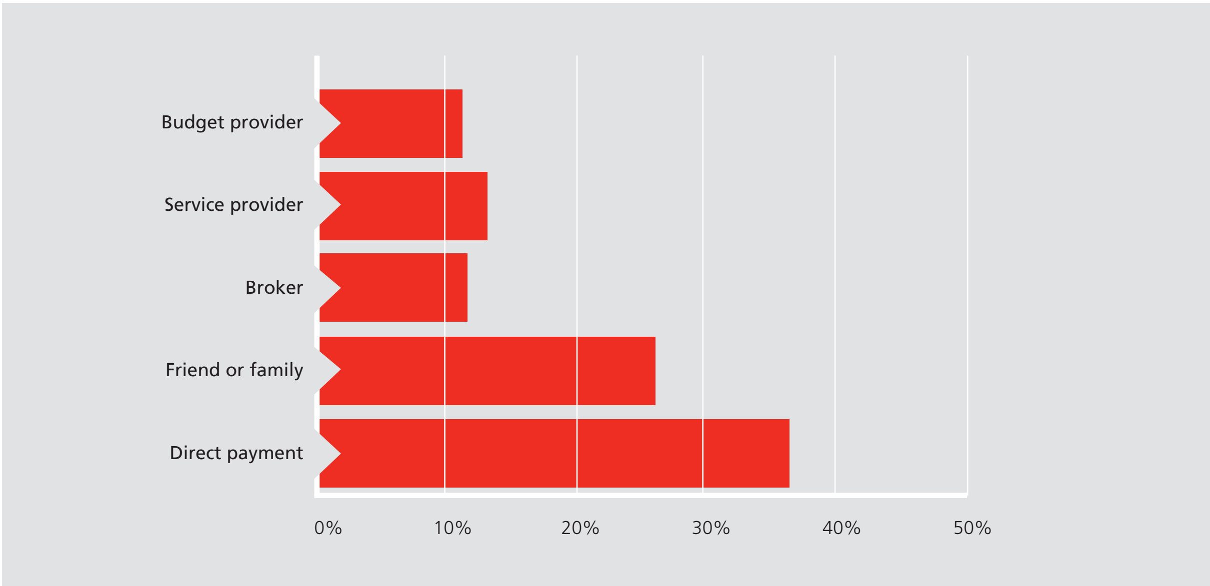
The POET survey asks personal health budget holders several questions about how they are managing personal health budgets and what support people have had throughout the personal health budget process.

We also checked for any differences in personal health budget usage and support by gender, age band and self-reported health status.

How do people manage their personal health budgets?

Figure 2 shows the different ways that people managed their personal health budgets. Overall, in this sample of POET survey respondents, people most commonly managed their personal health budget through direct payments paid to them (36.7%), followed by direct payments looked after by a friend or family member (26.2%). Personal health budgets managed by a service provider (13.1%), council or NHS-managed personal health budgets (11.1%) and personal health budgets managed by a broker (11.5%) were less common.

FIGURE 2: Management of personal health budgets

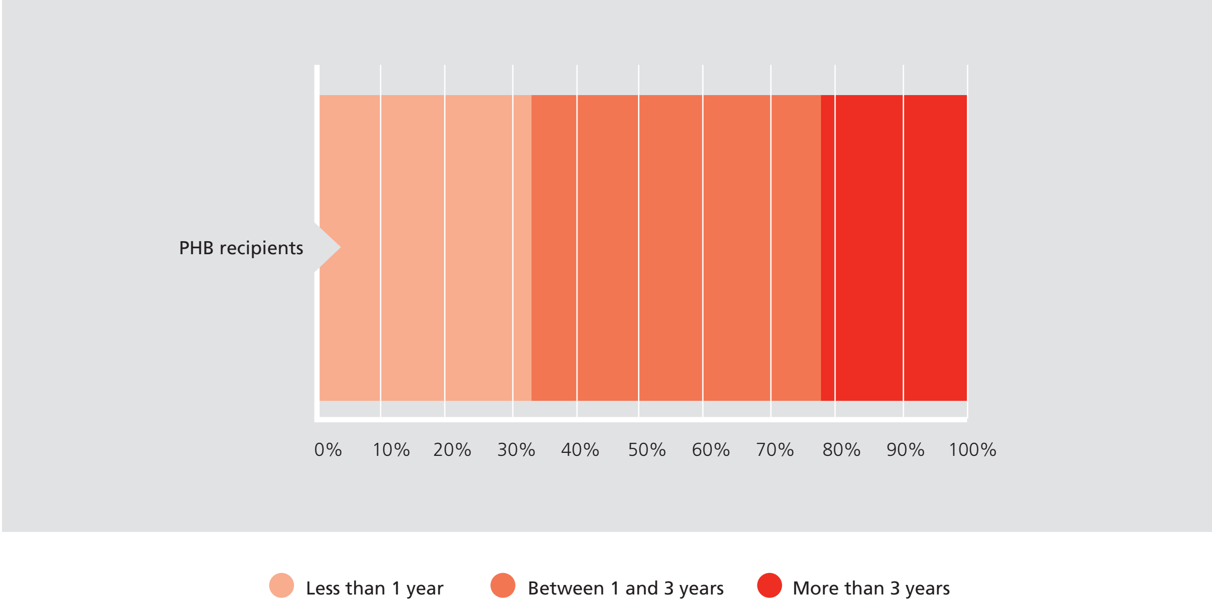


How long have people held a personal health budget?

Figure 3 shows how long POET survey respondents have held a personal health budget. Approaching a half (44.1%) of respondents had held their personal budget between a year and 3 years, just under a third (32.1%) for less than a year, and just over one fifth (22.1%) for more than three years.

There were no differences in the length of time people had held a personal health budget by gender, age or self-reported health status. People managing their budget via a direct payment paid directly to them were more likely than other budget holders to have held their budget for either less than 1 year or for more than 3 years (chi-square=12.84; df=2; p=0.002). There were no other associations between type of budget and length of time the budget had been held.

FIGURE 3: Length of time people had held their personal health budgets

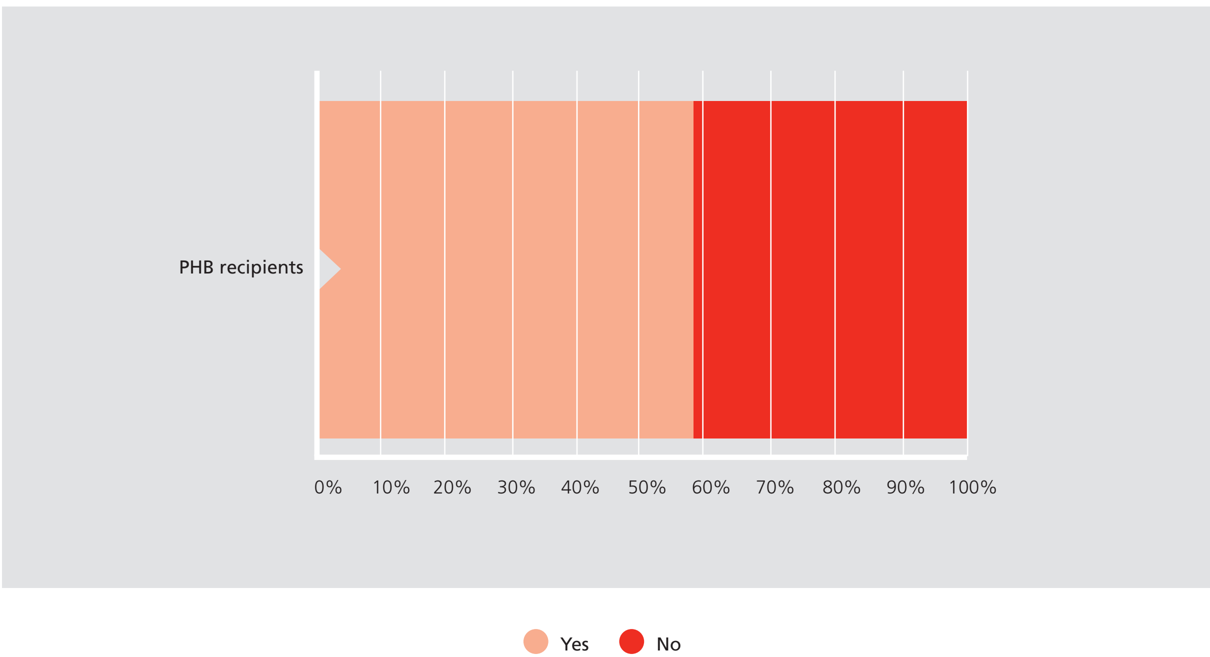


Did people get local authority support before their personal health budget?

Figure 4 shows how many personal health budget holders had been receiving help from someone who was paid to support them before getting their personal budget. Overall, over half (58.8%) of respondents had been receiving social care support before the start of their personal health budget.

There were no differences in whether people had received previous local authority support by gender, age, self-reported health status or the type of personal health budget people held.

FIGURE 4: Previous social care support before the personal health budget



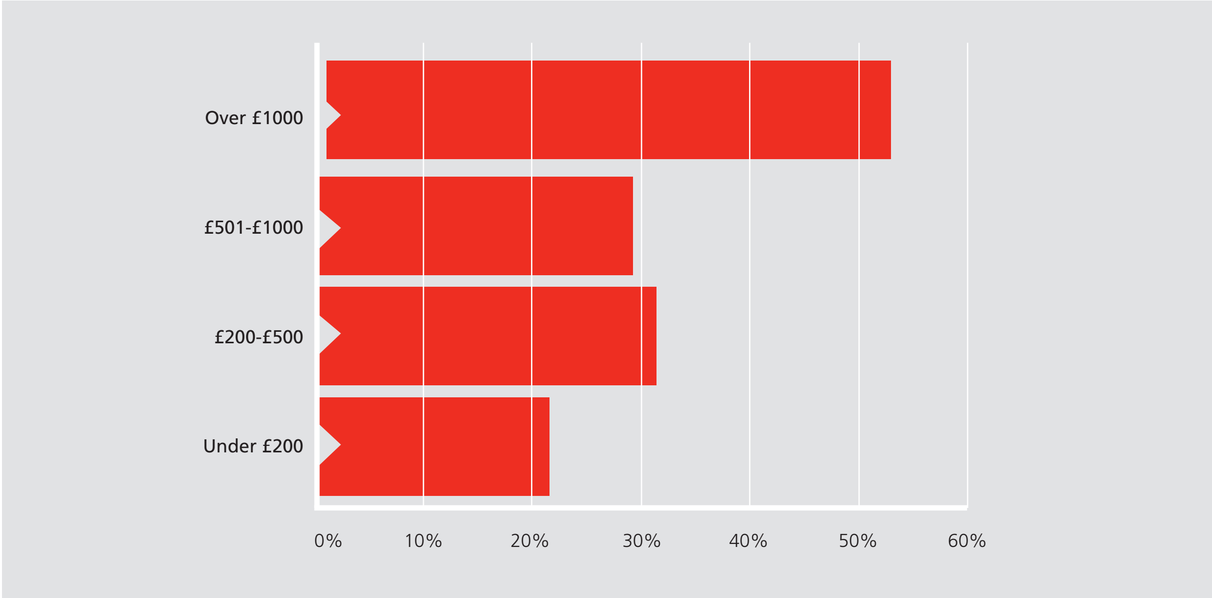
Yes No

The cost of personal budgets

The POET survey asked personal health budget holders whether they were told either the weekly amount of their personal health budget or the amount of a one-off personal budget payment, and they also asked whether they could provide an estimate of the amount.

Overall a majority of personal health budget holders (61.2%) reported having been told their weekly support costs or amount of one-off payment. There were no statistically significant differences in whether people had been told their support costs or not by gender, age, self-reported health status or type of personal budget.

FIGURE 5: Amount of money in a personal health budgets



Ammount of money in a personal health budget

Figure 5 shows that of the 138 people (45.6%) reporting a weekly amount for their personal budget: well over a third (39.1%) reported a budget over £1000 per week; around one fifth (21.7%) between £501 and £1000 per week; a quarter (23.2%) between £200 and £500 per week; the remainder (15.9%) less than £200 per week.

Of the 48 people (15.8%) reporting a one-off payment: over a third (39.5%) reported a one-off payment up to £1,000; a third (31.2%) a payment between £1,001 and £2,000; and under a third (31.2%) a payment above £2,000.

There were no statistically significant differences in the estimated annual amount of people's weekly or one-off personal health budgets by gender, age or self-reported health status. The number of people reporting an estimated amount of their weekly personal health budget or their one-off payment was too few to allow for analysis of the amount of budget by type of budget.

Support for planning personal health budgets

The POET survey asked a range of questions about how people were supported when planning their personal health budget, including who supported them and whether their views were included in different aspects of the personal health budget process.

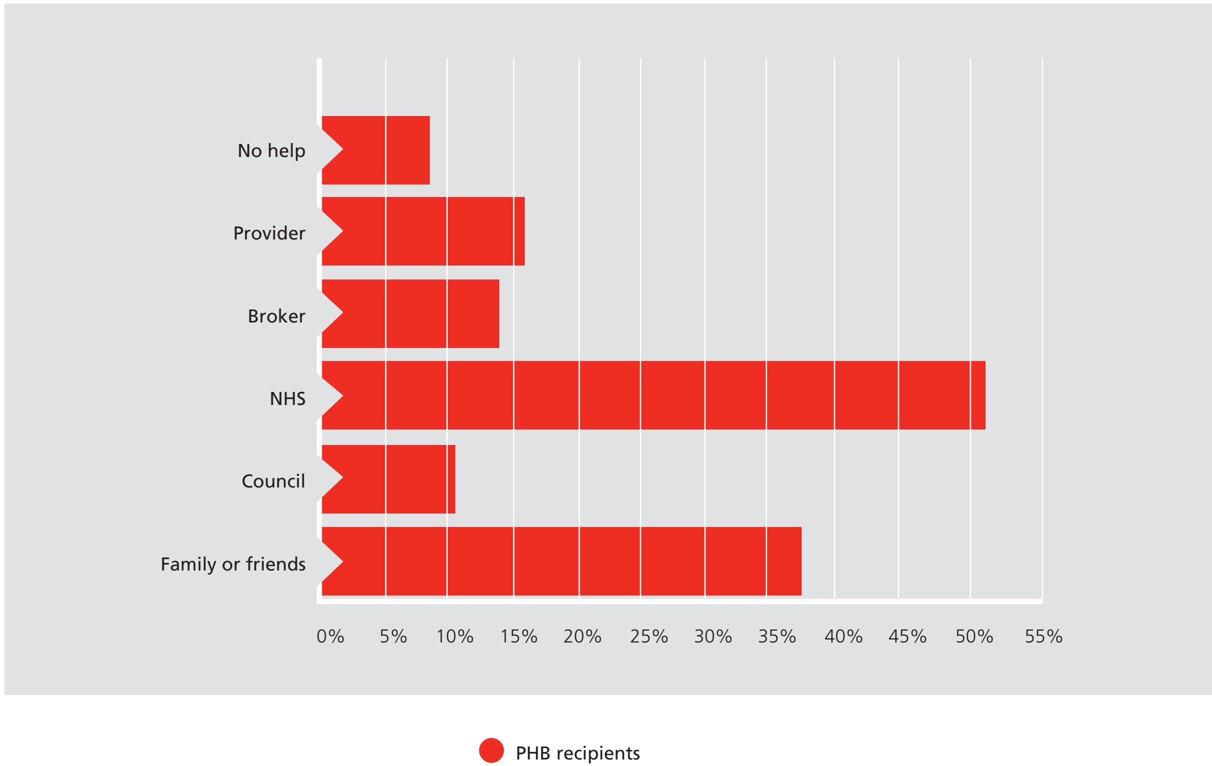
Figure 6 shows how many people used various sources of support in planning how to use their personal health budget, respondents could indicate they had support from more than one source. The two main areas of support were from the NHS (50.5%), and from family or friends (36.6%), with support to plan from other areas also available to some people, providers (15.8%), brokers (13.9%). 8.8% of people said they had no help to plan.

There were a number of differences in sources of help for planning according to the type of personal budget people held:

- **People with a direct payment paid directly to them were more likely to do their planning themselves without any help (Fisher's exact p=0.038).**
- **People with a direct payment managed by a friend or family member were more likely to get help with planning from family or friends (Fisher's exact p<0.001).**
- **People with a direct payment managed by a broker were more likely to get help with planning from the council (Fisher's exact p=0.005).**
- **People with a budget managed by a provider were more likely to get help with planning from family or friends (Fisher's exact p=0.019) and also from an independent person (Fisher's exact p=0.014).**
- **People with a budget managed by the NHS or council were more likely to get help with planning from a service provider (Fisher's exact p<0.001)**

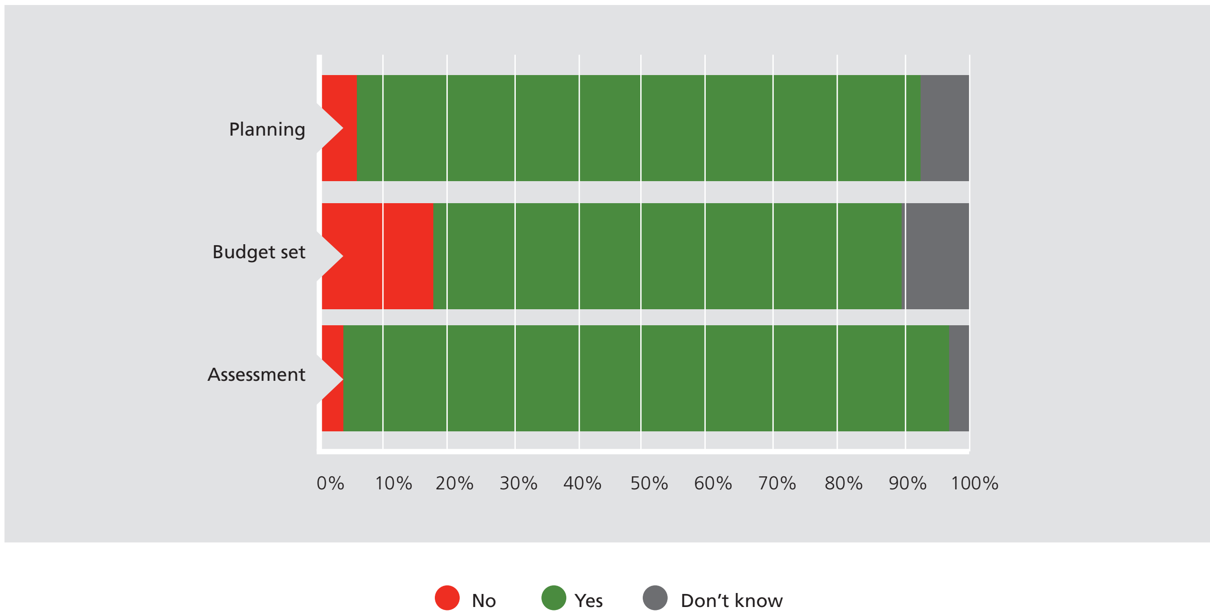
There were no differences in sources of help to plan according to people's age or gender.

FIGURE 6: Support for planning personal health budgets



Finally, the POET survey asked respondents whether their views were included in various aspects of the personal health budget process (see Figure 7). The overwhelming majority of personal health budget holders reported their views had been included when their needs were assessed (92.9%) and when their plan was developed (86.6%); a less substantial majority reported their views had been included when their budget was set (71.9%).

FIGURE 7: Were people's views included in the personal health budget process?



Was the personal health budget process difficult for people?

As Figure 8 reports, the POET survey asked several questions to personal health budget holders about whether various aspect of the personal health budget process were easy or not for them.

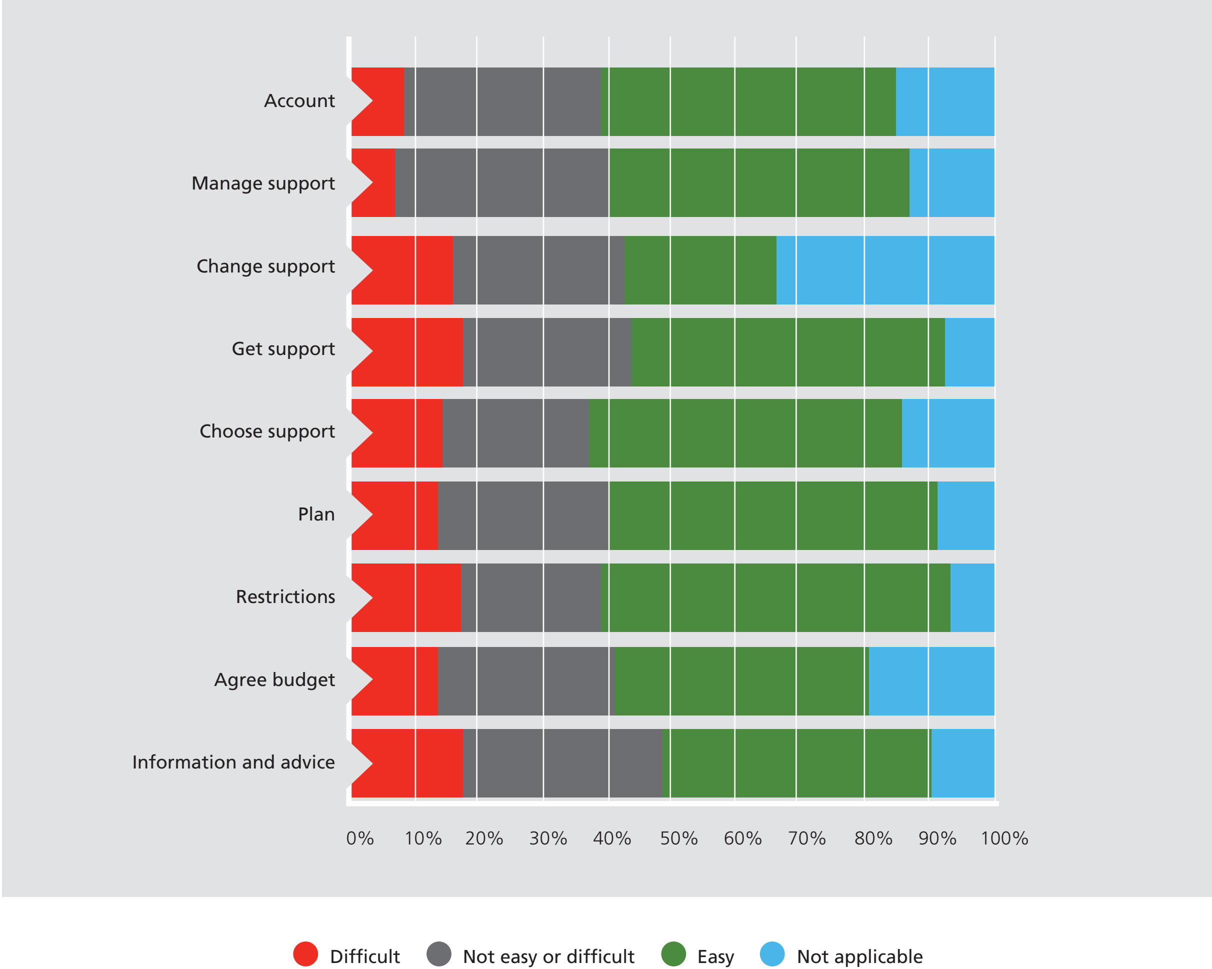
As many people's budgets were of relatively short duration or made as a one-off payment, it is possible that not all of these questions would have been relevant to all respondents at the time they completed the survey. Respondents were given an option to say if an area of the process being asked about was not applicable to them. Here percentages shown are of those saying that aspect of process was relevant to them.

Around 15% of personal health budget holders said that aspects of the process were difficult for them in 9 areas we asked about: information and advice (17.7%); understanding how budget could and couldn't be used (17.1%); getting support (17.3%) and changing support (15.8%).

As the NHS was supporting a substantial majority of people (68.5%), it was not possible to investigate whether there were differences in how easy or difficult different types of organisation made the process.

People with a direct payment paid directly to them were more likely to report that it was easy for them to manage their support (Fisher's exact p=0.049) and get the support they wanted (Fisher's exact p=0.004). People with a direct payment managed by a broker were more likely to report that it was easy to change their support (Fisher's exact p=0.028). There were no other differences according to personal budget type. There were also no differences according to people's age or gender.

FIGURE 8: Was the personal health budget process easy or difficult?



Have personal health budgets made a difference to people's lives?

POET asks personal health budget holders whether their personal health budgets have made a difference to various aspects of their lives, and if so whether this difference has been positive or negative.

Figure 9 summarises the impact of personal health budgets on the 15 areas of people's lives we asked about. The POET personal health budget survey does not represent a nationally representative sample, and because of this overall statistics concerning outcomes must be treated with caution. Respondents were offered an option to indicate if the area of life being asked about was not relevant to them – the percentages shown here are of those saying that the particular area of life was relevant to them.

Overall, over 80% of personal health budget holders reported their budget having a positive impact on their quality of life (84.7%), independence (81.4%), and arranging support (83.5.1%).

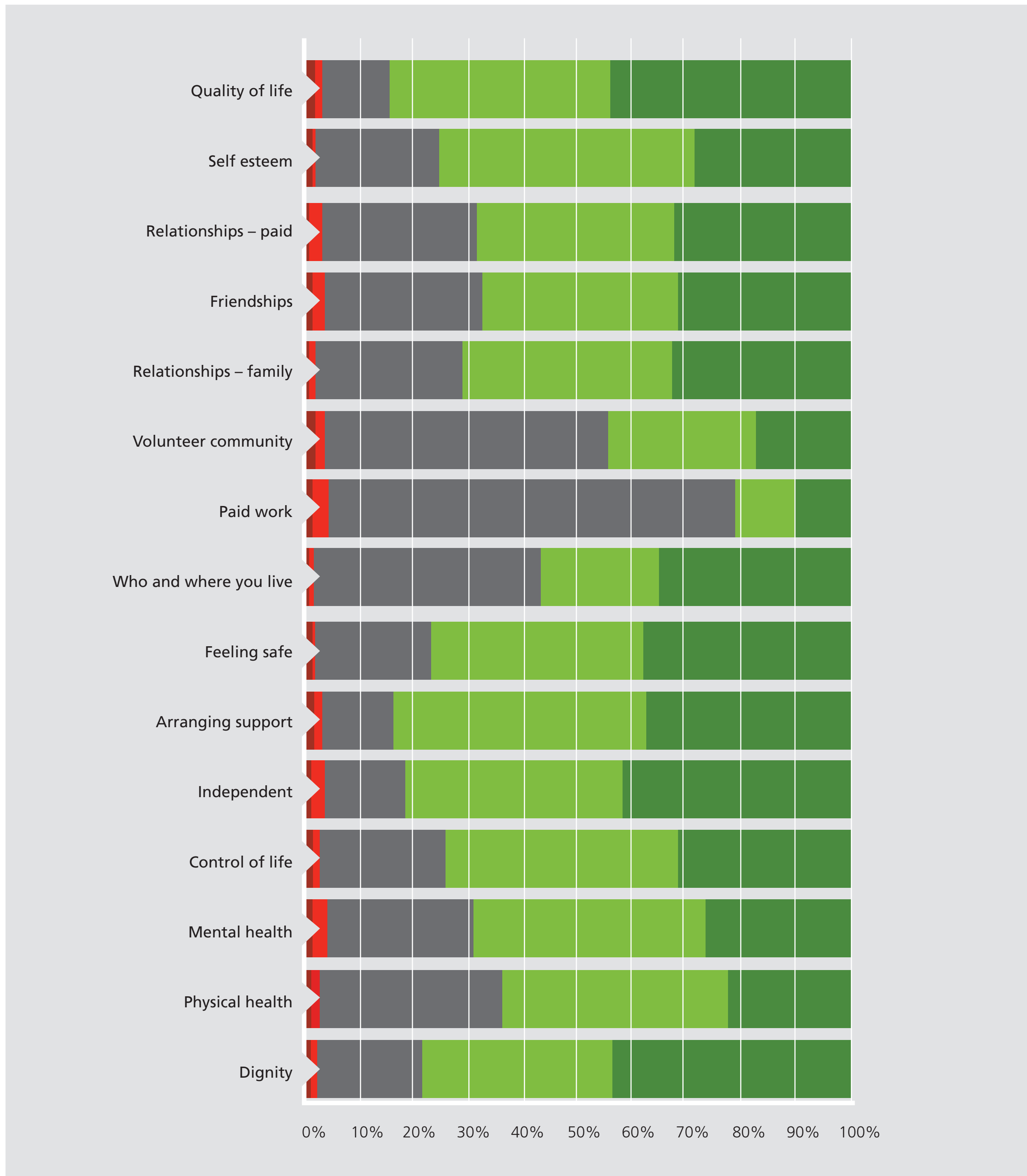
Over 70% of personal health budget holders reported their budget having a positive impact on their self-esteem (75.5%), feeling safe (76.3%), control over life (74.2%), family relationships (71.2%)and dignity (78.2%).

Over 60% of personal health budget holders reported their budget having a positive impact on their relationships with people paid to support them (68.5%), friendships (67.3%), physical health (63.3%) and mental health (69.3%).

Overall, small numbers of people (between 1.5% and 4.5%) reported their personal health budget having a negative impact on any of these 15 aspects of people's lives.

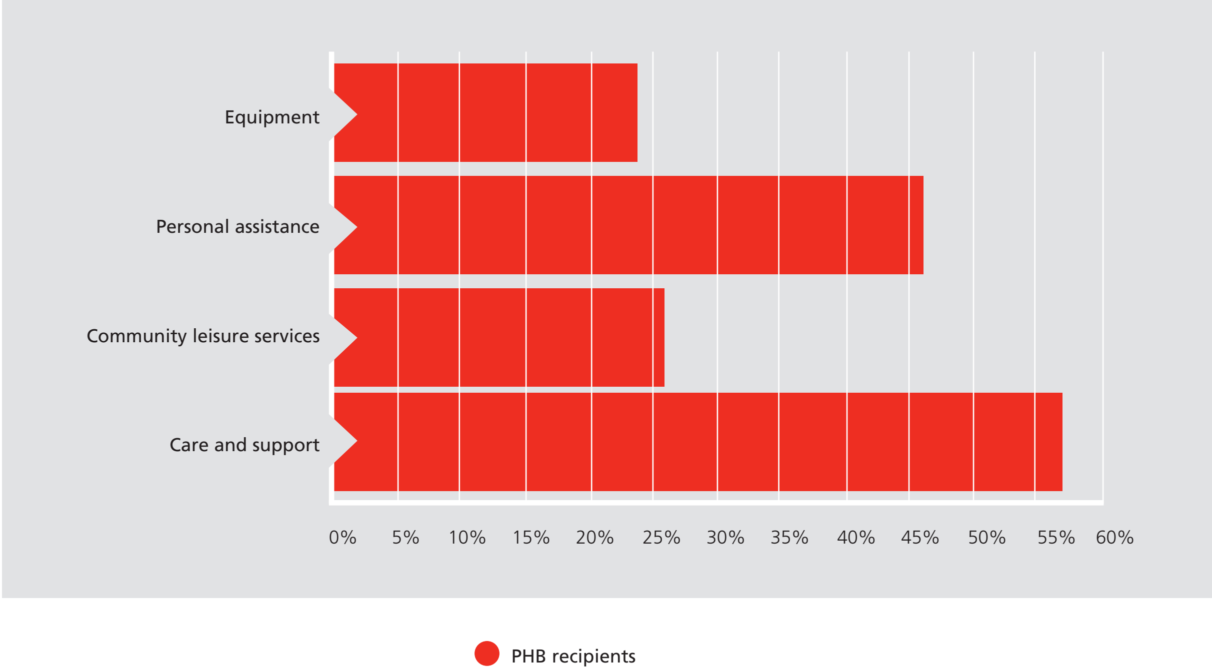
People who felt their views were fully included at key parts of the personal budget process were more likely to report a positive impact of their budget.

FIGURE 9: Outcomes of personal health budgets



Finally, we asked personal health budget holders how they had used their personal health budget, specifically whether the budget had been used for: care and support, community and leisure services, a personal assistant, or equipment. People could choose more than one option. The most common way to use their budget was on care and support services (59.6%), followed by personal assistants (48.3%), community and leisure services (26.8%), and equipment (25.2%).

FIGURE 10: How personal health budget holders' used their budget.



PHB recipients

What worked well, what didn't work well and what would personal health budget holders change

Respondents were asked to comment about their experience of having a personal health budget. We asked people what worked well, what didn't work well and what specific changes they would make. Three quarters of people commented on what had worked well (79.5%), nearly two thirds commented on what had not worked well (64.5%), and half made comments suggesting changes (52.3%).

The length of response varied from a couple of words to several sentences, with most people providing just a single sentence. Responses tended to illustrate peoples personal experience of the process of taking control of a personal health budget or the impact the personal budget had on their life.

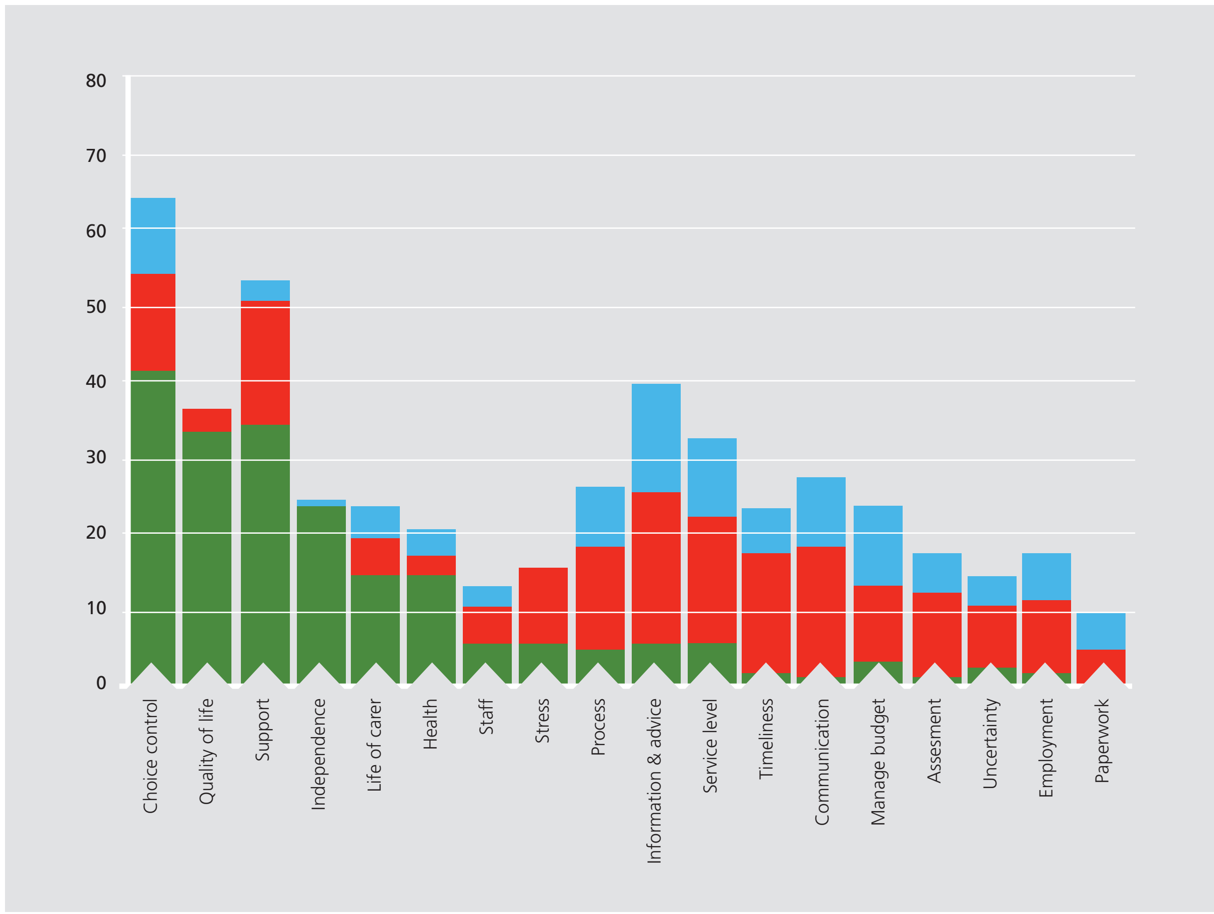
In addition to their experience of personal health budgets, comments covered a wide range of issues., In particular people described their personal circumstances, the reason why they had a personal health budget and how important the support was to them.

Gathering and reviewing free text responses has allowed us to identify several common themes (see table below). Figure 11 provides an analysis of the comments by theme.

Personal health budgets had a positive impact on peoples quality of life, independence, and arranging support.

CATEGORIES	
Choice & Control	The degree of choice and control the personal health budgets had allowed over treatment and support, and in other aspects of life.
Quality of life	Life experiences affected by having a personal budget including; impact on emotional wellbeing, ability to manage their health condition and family relationships.
Support/Treatment	The nature, location, timing, and type of treatment or support available as a result of the personal health budget.
Independence	The impact of the personal health budget on the person's mobility and access to local community facilities and services. Remaining in their own home rather than in hospital or a care home.
Life Carer	The impact of the personal health budget for the person they care for on the carer's life.
Health	The impact that the personal health budget has on the person's physical or mental health. This includes how the budget impacted on their recovery or reduced the impact of their condition on their life.
Staff	The knowledge, understanding, attitudes of staff – mainly council staff responsible for referrals, assessments and support planning.
Stress/Worry	Emotional pressure or worry and stresses caused or relieved by the personal budget, including responsibility of managing the budget. Stress and worry alleviated by the support provided through a personal budget.
Process	The experience of getting and controlling a budget.
Information and Advice	Information, advice, guidance and support available to people taking control of a personal health budget. This includes clear policy and procedure and details of service options. Information about how the process worked, what was or was not permitted, and information about available support options.
Funding/Service Level	The amount of money in the budget or service available as a result of having a budget.
Timeliness	Speed with which the personal budget was allocated and the time it took to establish an appropriate support package.
Communication	The experience of communicating with staff, in particular difficulty accessing individuals. The impact of communication between organisations.
Managing the budget	The experience of controlling and accounting for a personal health budget.
Assessment	The interactions with professionals assessing the nature and level of the persons needs.
Uncertainty	Lack of confidence that the personal health budget will remain in place over time. Anxiety about the future.
Employment	Issues associated with recruiting and managing staff who provide support.
Paper work	The paperwork involved in applying for or accounting for a budget

FIGURE 11: Personal budget holders' comments on what worked well, what didn't work well and what should change.



What factors are associated with positive outcomes for personal health budget holders?

Figure 11 on page 25 shows how personal budget holders feel their personal health budget has affected (or not) 15 areas of their lives. In this section of the report we will ask four further questions:

1) Are there differences in the outcomes of personal health budgets depending on age, gender or current health status?

2) Are aspects of personal health budget usage (organisation administering the personal health budget, previous local authority support, length of time with personal health budget, type of personal health budget, knowledge of the cost of personal health budget, support in personal health budget planning, feeling that your views are included in the support plan) associated with positive outcomes?

3) Are personal health budget holders' perceptions of the processes involved in holding a personal health budget associated with positive outcomes?

4) Are what people have spent their personal health budget on associated with positive outcomes?

To address these questions, we checked whether there were associations between all the factors mentioned above and better outcomes on all the outcome indicators.

To make interpretation easier, we will express any associations found as odds ratios (for example, if people were helped to plan their personal health budget, what the odds of them reporting a positive impact of their personal health budget compared to if they had not been helped to plan their personal budget). An odds ratio of 1 would mean that a positive impact was no more or less likely if people had been helped to plan or not. An odds ratio significantly less than 1 would mean that a positive impact was less likely if people had been helped to plan (so an odds ratio of 0.5 would mean that people were half as likely to report a positive impact if they had received help to plan). An odds ratio significantly more than 1 would mean that a positive impact was more likely if people had been helped to plan (so an odds ratio of 2 would mean that people were twice as likely to report a positive impact if they had received help to plan). Odds ratios are a helpful way of showing how big an effect is, as well as whether it is statistically significant or not.

Because of the smaller numbers of people reporting the estimated amount of their personal health budget, we did not conduct analyses of the relationship between the amount of people's budgets and outcomes.

However, it is important to say that we can only report associations between factors and outcomes, and if there is an association we cannot say that the process factor caused the outcome (for example, it could be that a third factor we didn't measure caused both the process factor and the outcome). It is important to bear this in mind, along with the relatively small numbers of people who responded, when interpreting the results we report below.

The tables following report the odds ratios for each factor against each outcome indicator. If an odds ratio shows that a factor is significantly associated with the outcome indicator (so the pattern of results has a less than 5% chance of being due to chance) than there is an asterisk next to the number. All of these significant associations are reported in the text. Odds ratios significantly greater than 1 are shaded green; odds ratios significantly less than 1 are shaded red.

Table A on page 28 shows whether three personal factors (the personal health budget holder being 65 years old or older, female, or reporting themselves as in fair/bad/very bad health), the organisation administering the personal health budget (NHS, Council, or both), and whether the personal health budget holder had been receiving social services support before the personal health budget or not, were associated with personal budget holders reporting a positive impact of their personal health budget on 13 areas of people's lives we asked about (the numbers of people reporting a positive impact on paid work and volunteering were too small for odds ratios to be calculated).

Table A shows firstly that people's age or gender were unrelated to any of the outcome indicators.

Table A also shows that people with poorer self-reported health were at least twice as likely to report a positive impact of personal health budgets than people with good self-reported health, on quality of life in: quality of life, self-esteem, and relationships with family, friends and others paid to support the person.

There were relatively few associations between the agency organising the personal health budget and perceived impact. People with NHS-organised budgets were three times more likely to report a positive impact of their budget on arranging their support. People with council-organised budgets were less than half as likely to report a positive impact of their budget on arranging their support, or on their physical or mental health. People with budgets organised by both the NHS and the council were less than half as likely to report a positive impact of their budget on their self-esteem.

Finally, there were no associations between perceived impact and whether the person had been getting council support before their personal health budget.

TABLE A: Personal factors and aspects of the organisation of people's personal health budgets: Associations with positive outcomes for personal health budget holders

Outcome	Factors potentially associated with positive outcome: Personal factors and the main PHB organisation						
	65 years old or over	Female gender	Fair/bad/ very bad health	NHS organ-ising PHB	Council organ-ising PHB	Both NHS & Council organ-ising PHB	Council support before PHB
Quality of life	0.83	1.06	2.39*	2.00	0.61	0.51	0.96
Self-esteem	0.83	0.91	3.67*	1.92	1.01	0.39*	0.88
Relationships – paid	1.32	1.06	2.92*	1.42	0.53	0.94	0.91
Friends	0.74	0.76	2.61*	1.20	0.93	0.80	1.16
Relationships – family	0.83	0.99	2.96*	1.24	0.69	0.93	0.82
Volunteer – community	n/c	n/c	n/c	n/c	n/c	n/c	n/c
Paid work	n/c	n/c	n/c	n/c	n/c	n/c	n/c
Who and where you live	1.81	1.23	1.23	1.31	0.87	0.73	1.31
Feeling safe	1.52	0.83	1.31	1.29	0.69	0.89	1.47
Arranging support	0.98	0.83	1.22	3.09*	0.27*	0.54	0.73
Independence	0.77	0.84	1.06	1.36	0.81	0.74	0.83
Control over life	0.59	1.28	1.38	1.74	0.53	0.68	0.78
Mental health	0.96	0.88	1.27	1.59	0.37*	1.11	0.85
Physical health	0.92	1.11	1.09	1.50	0.43*	1.09	0.92
Dignity	0.88	1.20	1.61	1.22	0.89	0.80	0.94

n/c=Odds ratio not calculable

Table B on page 29 shows potential associations between various aspects of the personal health budget (having held a budget for over a year, type of personal health budget, whether the person knows their support costs) and positive outcomes for 13 outcome indicators.

The length of time people had held their personal health budget was associated with nine of the 13 outcome indicators. People who had held their budget for more than a year were at least twice as likely to report a positive impact of their budget on their quality of life, self-esteem, relationships with family and with people paid to support them, where and with whom they lived, feeling safe in and outside their home, arranging their support, being as independent as they wanted to be, and being supported with dignity.

There were relatively few associations between the type of personal budget people held and perceptions of positive impact. People with a direct payment paid directly to them were half as likely to report a positive impact of their budget on where and with whom people lived, and feeling safe. People with a direct payment paid to a family member or friend were more than twice as likely to report their budget having a positive impact on where and with whom people lived, and being supported with dignity. People with a budget managed by the NHS or local council were more than four times as likely to report a positive impact of their budget on their physical health and on feeling safe.

People knowing the amount of their budget was also not associated with any outcome indicators.

TABLE B: Aspects of the personal health budget: Associations with positive outcomes for personal health budget holders

Outcome	Factors potentially associated with outcome: The personal health budget						
	PHB held for >1 year	DP paid to own account	DP paid to broker	DP paid to family or friend	Provider-managed PHB	NHS/ council-managed PHB	Know support costs
Quality of life	2.63*	0.54	0.56	1.99	2.31	6.56	0.66
Self-esteem	1.90*	1.22	0.52	0.81	2.91	1.79	0.88
Relationships – paid	2.01*	0.90	1.01	1.29	1.92	1.02	0.83
Friends	1.46	0.68	1.28	1.18	1.68	1.99	1.14
Relationships – family	2.37*	0.87	1.13	0.92	1.38	2.76	0.90
Volunteer – community	n/c	n/c	n/c	n/c	n/c	n/c	n/c
Paid work	n/c	n/c	n/c	n/c	n/c	n/c	n/c
Who and where you live	2.21*	0.50*	0.73	2.31*	1.54	1.73	1.21
Feeling safe	2.46*	0.51*	0.68	2.04	1.52	4.68*	1.12
Arranging support	2.66*	0.87	0.76	1.41	1.31	1.97	1.05
Independence	3.23*	0.62	1.27	2.12	0.86	1.76	0.93
Control over life	1.64	1.35	0.73	0.73	1.10	1.93	0.68
Mental health	1.12	1.19	0.67	0.80	1.02	2.92	0.97
Physical health	1.00	1.26	0.61	0.67	0.75	4.26*	0.84
Dignity	2.29*	0.69	0.66	2.25*	0.69	2.96	1.02

n/c=Odds ratio not calculable

Table C on page 31 shows potential associations between various aspects of the personal health budget planning process (who helps the person to plan) and positive outcomes for 13 outcome indicators.

In terms of sources of help for planning (please also note that these sources of support are not mutually exclusive; people could record getting help to plan from more than one source), the most consistent finding was that people who did their planning themselves without any help were less than half as likely to report a positive impact of their budget on 11 out of the 13 outcomes where analysis was possible. In terms of specific sources of support:

- People who got help to plan from someone in the NHS were more likely to report a positive impact of their budget on feeling safe, arranging support, being as independent as they wanted to be, and their physical health.
- People who got help to plan from a service provider were more likely to report a positive impact of their budget on their quality of life, mental health, and physical health.
- People who had help to plan from family/friends were more than twice as likely to report their budget having a positive impact on their quality of life.
- People who got help from someone independent of the council or NHS were half as likely to report their budget having a positive impact on them being supported with dignity.
- There were no associations between people getting help to plan from the council and any outcome indicators.

People who did their planning themselves without any help were less than half as likely to report a positive impact of their budget.

TABLE C: Aspects of support planning: Associations with positive outcomes for personal health budget holders

Outcome	Factors potentially associated with outcome: Support in the PHB planning process					
	Family/ friends help to plan	Council helps to plan	Plan without help	NHS helps to plan	Independent person helps me to plan	Provider helps me to plan
Quality of life	2.38*	0.66	0.37*	1.38	0.63	4.68*
Self-esteem	1.09	1.02	0.34*	1.65	0.90	1.88
Relationships – paid	1.50	0.86	0.34*	1.33	0.95	1.25
Friends	1.63	1.17	0.54	1.64	0.93	1.51
Relationships – family	1.32	1.11	0.32*	1.46	1.04	1.97
Volunteer – community	n/c	n/c	n/c	n/c	n/c	n/c
Paid work	n/c	n/c	n/c	n/c	n/c	n/c
Who and where you live	1.43	1.38	0.12*	1.69	1.21	1.44
Feeling safe	1.58	1.63	0.28*	3.33*	0.88	1.03
Arranging support	1.29	1.27	0.33*	2.63*	0.73	2.26
Independence	1.76	1.48	0.26*	2.99*	0.71	2.20
Control over life	1.03	1.31	0.38*	1.71	0.92	1.80
Mental health	1.37	1.19	0.56	1.61	1.00	2.70*
Physical health	0.93	1.12	0.29*	1.68*	0.87	2.37*
Dignity	1.46	2.01	0.31*	1.64	0.47*	1.18

n/c=Odds ratio not calculable

Table D on page 33 shows potential associations between people's perceptions of whether their views were fully included at three points in the personal health budget planning process and positive outcomes for 13 outcome indicators.

A large majority of respondents to the POET survey reported that their views were fully included when their needs were being assessed and when the support plan was being written, meaning that there was little variation in the data for odds ratios to be calculated.

Nevertheless, people who felt their views were fully included when their support needs were being assessed were between four and 24 times more likely to report a positive impact of their budget on all 11 outcome indicators where calculations were possible.

People who felt that their views were fully included when their support plan was being written were between two and six times more likely to report a positive impact of their budget on 11 out of 13 outcome indicators where calculations were possible.

Although still a majority, fewer people reported that their views were fully included when the amount of their personal budget was being set, given more variation for odds ratio calculations. If people felt their views were fully included when the budget was being set, they were between three and seven times more likely to report a positive impact of their budget on all 13 outcomes indicators where calculations were possible.

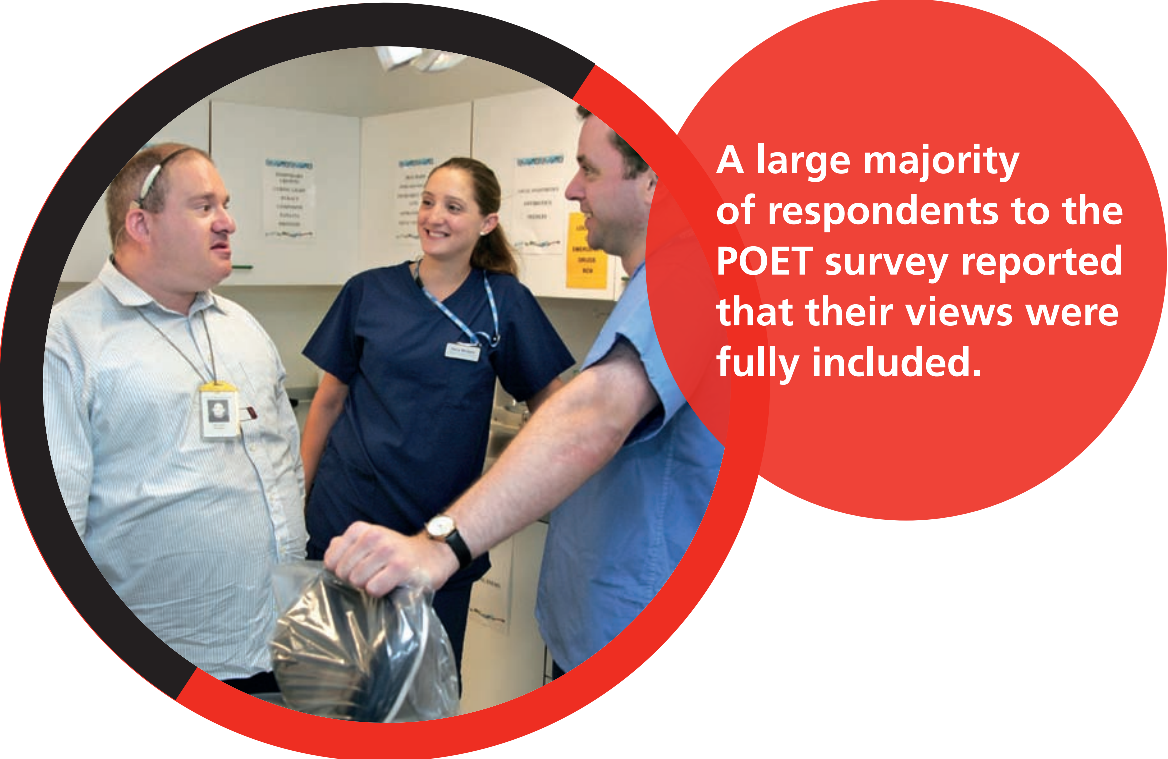


TABLE D: Views included in the planning process: Associations with positive outcomes for personal health budget holders

Outcome	**Factors potentially associated with outcome: Views included in the PHB planning process**		
	Views included when needs assessed	Views included when budget amount was set	Views include when support plan written
Quality of life	10.74*	4.20*	4.00*
Self-esteem	23.88*	4.39*	6.09*
Relationships – Paid	5.82*	3.38*	2.05
Friends	13.34*	4.67*	3.20*
Relationships – Family	n/c	7.72*	3.81*
Volunteer – Community	n/c	n/c	n/c
Paid work	n/c	n/c	n/c
Who and where you live	n/c	3.91*	3.30*
Feeling safe	7.06*	6.32*	2.46*
Arranging support	6.73*	4.44*	4.89*
Independence	10.35*	6.14*	4.66*
Control over life	23.14*	3.57*	2.78*
Mental health	16.37*	3.38*	3.61*
Physical health	6.16*	2.94*	2.69*
Dignity	4.55*	5.49*	1.96

n/c=Odds ratio not calculable

Table E on page 35 shows potential associations between whether the organisation funding the person's personal health budget had made 9 aspects of the personal health process easy or not and 13 of the 15 outcome indicators we asked about.

As Table E shows, several aspects of the process were associated with several outcome indicators for personal health budgets holders. Specifically:

- People who found it easy to get information and advice about their personal health budget were more likely to report a positive impact of their budget on 10 out of 13 outcome indicators, particularly relating to independence, arranging support and quality of life (all three times more likely).
- People who found it easy to agree the amount of their budget were more than twice as likely to report a positive impact of their budget on their quality of life, their self-esteem, where and with whom they lived, and arranging support.
- People who found it easy to plan their support were more likely to report a positive impact of their budget on feeling safe, being as independent as they wanted to be, control over the important things in life, and their physical health.
- People who found it easy to choose their support were more likely to report a positive impact of their budget on where and with whom they lived, feeling safe, arranging support, independence, control over the important things in life, and their physical health.
- People who found it easy to get the support they wanted were more likely to report a positive impact of their budget on 11 of the 13 indicators analysed, particularly relating to arranging support (almost five times more likely).
- People who found it easy to change their support were at least twice as likely to report their budget having a positive impact on where and with whom they lived, arranging support, and their physical health.
- People who found it easier to manage their support day by day were more likely to report a positive impact of their budget on feeling safe, arranging support, independence, and being in control over the important things in life.
- There were few associations with outcome indicators for people finding it easy to know how they could spend their budget (where and with whom they lived) or finding it easy to account for their spending (arranging support).

TABLE E: Experience of the personal health budget process: Associations with positive outcomes for personal health budget holders

Outcome	Factors potentially associated with outcome: How easy are the following aspects of the PHB process								
	Get info & advice	Agree amount of PHB	How to spend PHB	Plan supp-ort	Choose support	Get support you want	Change your support	Man-age support day to day	Acco-unting for spend
Quality of life	3.29*	2.22*	0.84	1.54	1.53	1.92	1.32	1.03	1.39
Self-esteem	2.13*	2.58*	1.21	1.56	1.24	1.92*	1.31	1.08	0.93
Relation-ships – Paid	2.43*	1.77	0.82	1.44	1.44	1.87*	1.60	1.34	1.04
Friends	1.43	1.38	0.85	1.63	1.15	1.72*	0.95	1.19	0.82
Relation-ships – Family	1.59	1.34	0.93	0.98	1.05	1.52	1.22	0.95	0.67
Volunteer – Community	n/c	n/c	n/c	n/c	n/c	n/c	n/c	n/c	n/c
Paid work	n/c	n/c	n/c	n/c	n/c	n/c	n/c	n/c	n/c
Who and where you live	2.07*	2.05*	1.82*	1.36	2.18*	1.80*	2.07*	1.55	1.22
Feeling safe	1.60	1.36	1.13	1.87*	2.04*	2.22*	1.32	2.09*	1.07
Arranging support	3.66*	2.58*	1.35	1.86	2.36*	4.93*	2.74*	3.01*	2.29*
Indepen-dence	4.51*	2.02	1.22	2.81*	3.82*	3.17*	1.16	2.81*	1.74
Control over life	3.08*	1.89	1.23	2.27*	2.21*	2.61*	2.11	1.95*	1.80
Mental health	1.79*	1.52	0.79	1.45	1.21	1.81*	1.24	1.09	1.01
Physical health	2.63*	1.54	1.57	2.00*	2.11*	2.21*	2.20*	1.15	1.40
Dignity	1.97*	1.62	1.23	1.25	1.68	2.39*	1.35	1.37	0.87

Table F, below, shows potential associations between what the budget was spent on and 13 of the 15 outcome indicators we asked about.

People who used their budget for care and support services were more likely to report their personal health budget having a positive impact on their quality of life, relationships with friends, feeling safe, arranging support, and being supported with dignity.

People who used their budget for community and leisure activities were more likely to report their budget having a positive impact on their mental and physical health, their quality of life, and particularly arranging support (more than three times more likely).

People who used their budget for a personal assistant were more likely to report a positive impact of their budget on their relationships with friends and with people paid to support them, and using the budget for equipment was not associated with any outcome indicators.

TABLE F: What the budget is spent on: Associations with positive outcomes for personal health budget holders

Outcome	Factors potentially associated with outcome: What the budget is spent on			
	Care and support	Community and leisure	Personal assistant	Equipment
Quality of life	2.74*	2.70*	1.77	1.09
Self-esteem	1.59	1.89	1.59	1.25
Relationships – Paid	1.30	1.45	2.22*	0.98
Friends	1.82*	1.28	2.09*	0.78
Relationships – Family	1.65	1.67	1.74	0.83
Volunteer – Community	n/c	n/c	n/c	n/c
Paid work	n/c	n/c	n/c	n/c
Who and where you live	1.18	0.92	1.39	1.09
Feeling safe	2.13*	1.11	1.55	0.91
Arranging support	2.44*	3.35*	0.87	0.94
Independence	1.81	1.88	0.87	1.25
Control over life	1.41	1.67	1.24	0.85
Mental health	1.53	2.45*	0.95	1.57
Physical health	1.42	2.19*	0.74	1.18
Dignity	2.09*	1.96	1.18	1.06

n/c=Odds ratio not calculable

6 FINDINGS: CARERS

This section of the report presents findings for carers responding to the POET survey, including:

- Who responded to the POET survey?
- The circumstances of carers and the personal health budgets used by the people they are supporting?
- What difference personal health budgets make to carers' lives?
- What factors are associated with better outcomes for carers?

Who responded to the POET survey?

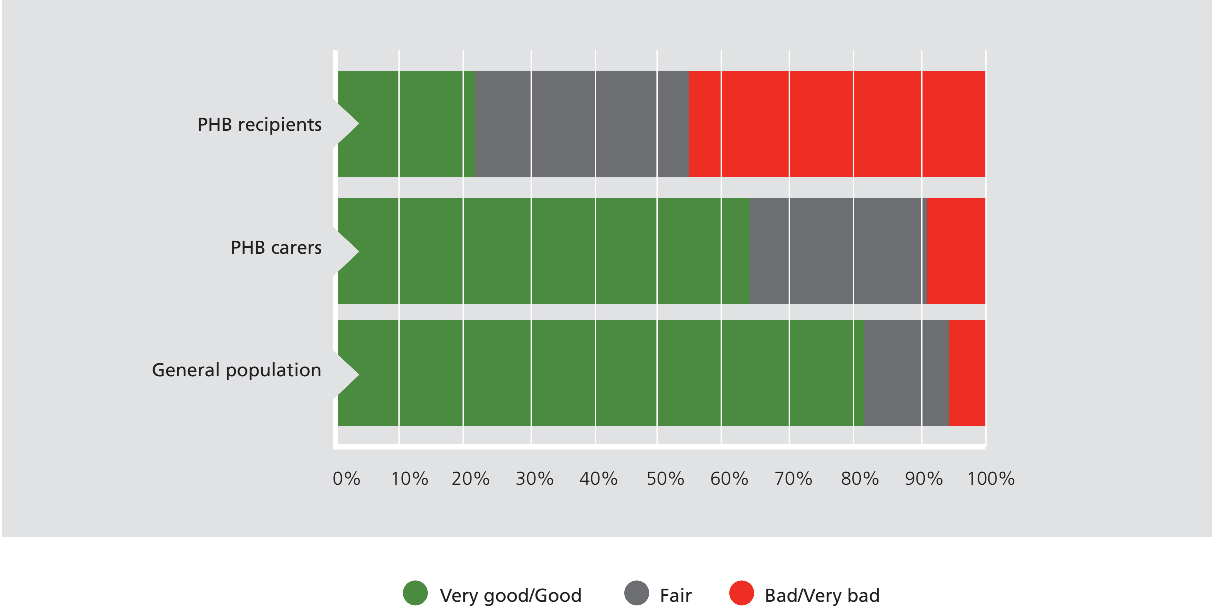
As mentioned earlier, a total of 247 carers completed the POET survey and gave their agreement for the information to be used. As people could choose not to complete particular questions within the survey, percentages are of the total responding to that particular question. In some areas respondents were asked to indicate if a particular question was not relevant to them.

- Most respondents (72.8%) were women.
- In terms of age, 14.3% of carers were aged 16-44 years, 57.4% were aged 45-64 years, and 28.3% were aged 65 years or over.
- Most respondents were White (93.3%).
- Most respondents were Christian (61.2%), with 26.8% reporting themselves to have no religion.
- Most respondents reported themselves to be heterosexual/straight (94.9%).
- A significant minority of carers (18.2%) reported themselves to have a disability, most commonly a physical disability (10.1%).

As we did with personal health budget holders, we asked the same question used in the 2011 census concerning people's self-rated general health in general to carers. As Figure 12 shows, the carers responding to the POET reported their health somewhere between that of the general population in England and that of the people they were supporting.

Well over half of carers (63.9%) reported their health as good or very good, compared to less than a quarter (21.5%) of personal health budget holders and over three-quarters (81.4%) of the general population. 9% of carers reported their health as bad or very bad, compared to almost a half (45.1%) of personal health budget holders and 5.4% of the general population.

FIGURE 12: Self-reported general health of carers vs personal health budget holders vs the general population of England (Census 2011)



Very good/Good   Fair   Bad/Very bad

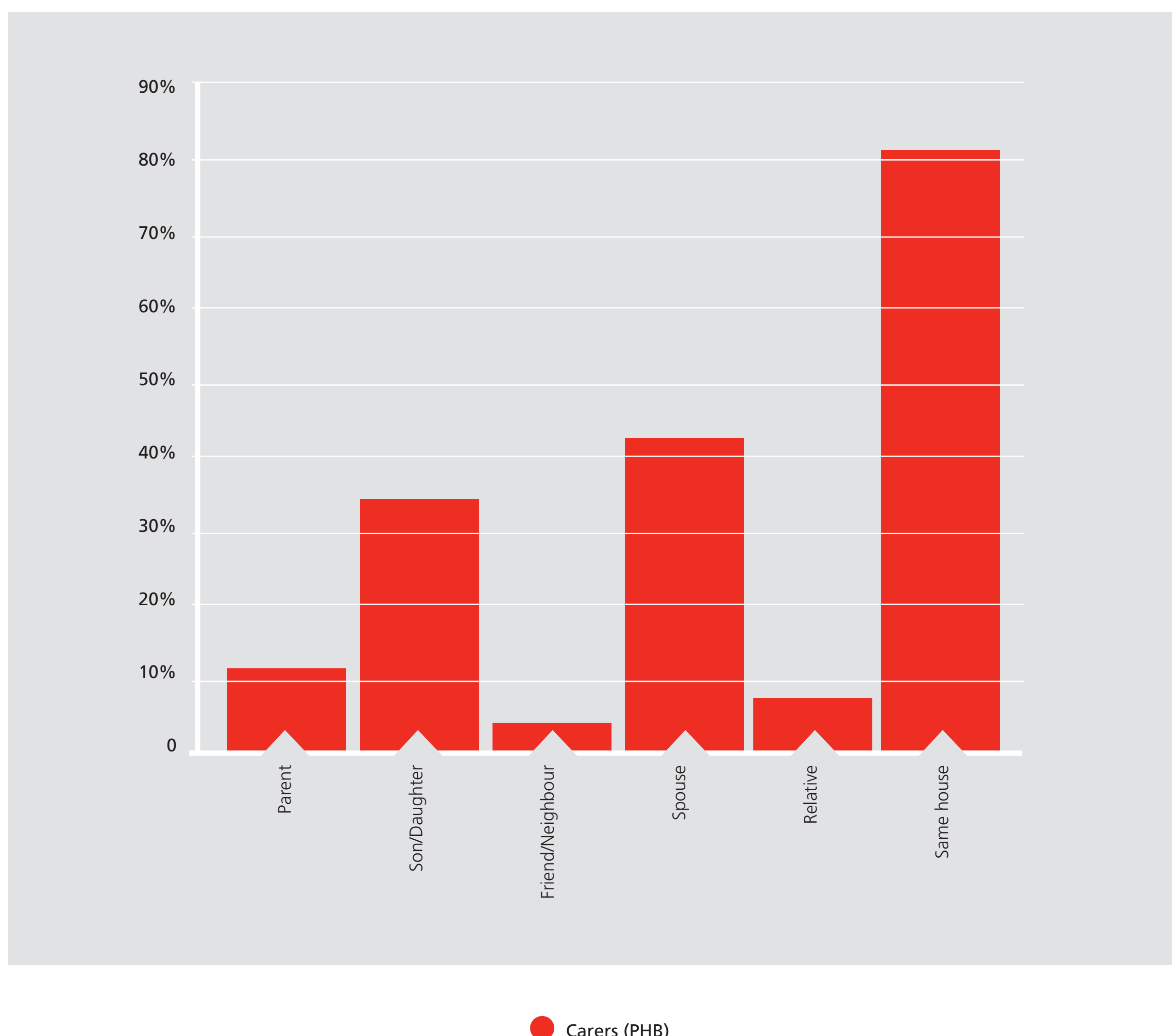
What are the circumstances of carers?

The POET survey asked carers a number of questions about their current circumstances regarding their caring role.

Figure 13 shows who carers in the POET survey were offering care and support to. Carers were most commonly caring for a partner/spouse (42. 1%), or a grown-up son or daughter (34.1%), followed by a parent (11.3%) or other relative (7.3%) with a smaller proportion of carers supporting an someone else e.g. a friend or neighbour (4.0%).

Figure 13 also shows that well over three quarters of carers (81.9%) were living in the same house as the person they were caring for.

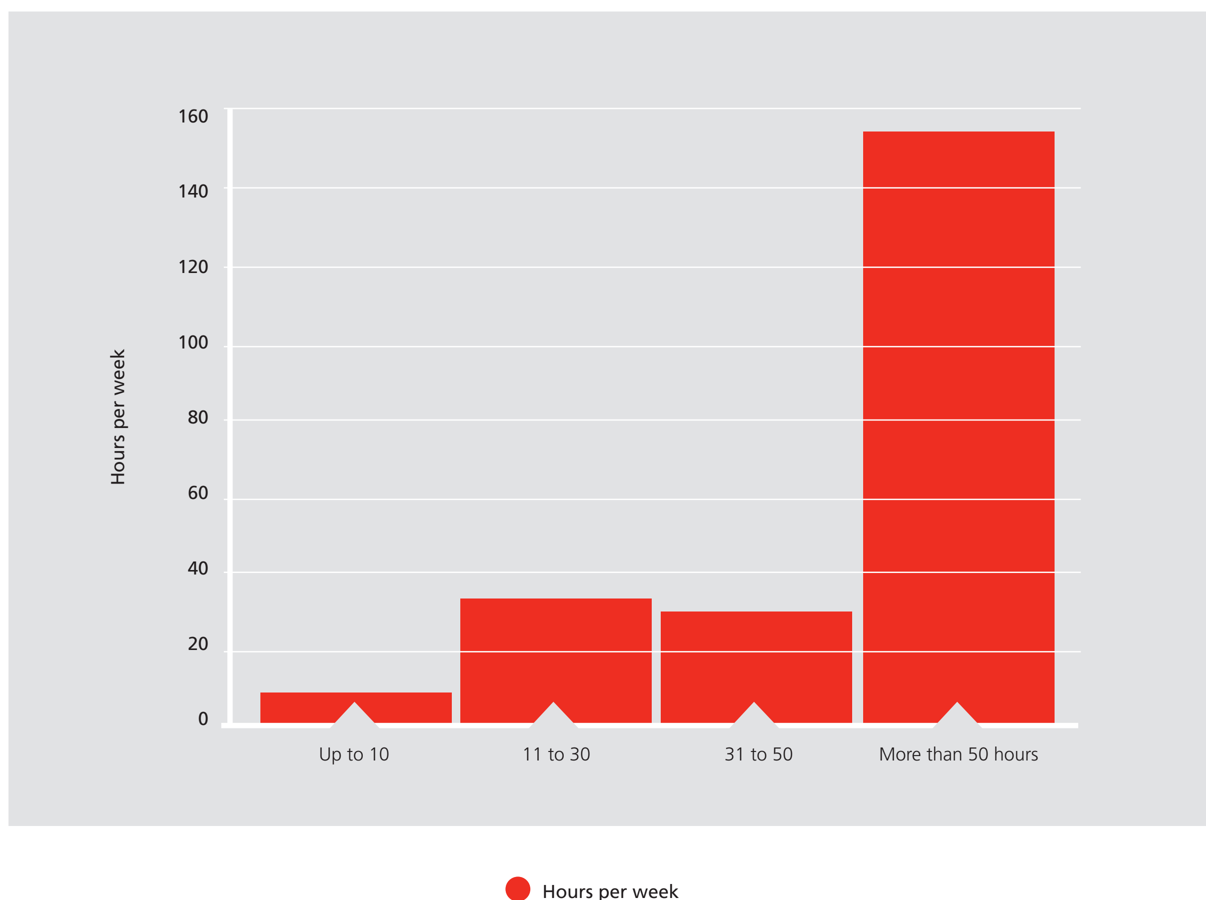
FIGURE 13: Who carers give care and support to, and if carers live in the same house as the person cared for



The POET survey also asked carers to estimate how many hours per week they would typically spend caring for the person they were supporting, in four bands (up to 10 hours; 11-30 hours; 31-50 hours; and 51 or more hours). As Figure 14 shows, more than two thirds (67.1%) of carers were caring for more than 50 hours per week.

Carers who were living in the same house as the person they were caring for (U=441.5, n=101, p=0.002) and carers who were caring for a son/daughter on average reported spending more hours caring (U=752.5, n=101, p=0.015)

FIGURE 14: Estimated hours per week spent caring



As with the POET survey for personal health budget holders, the POET survey asked carers how long the person they were caring for had been using a personal health budget, whether the person had been receiving paid support before getting a personal health budget, and whether the carer knew the amount of the personal health budget held by the person they were supporting.

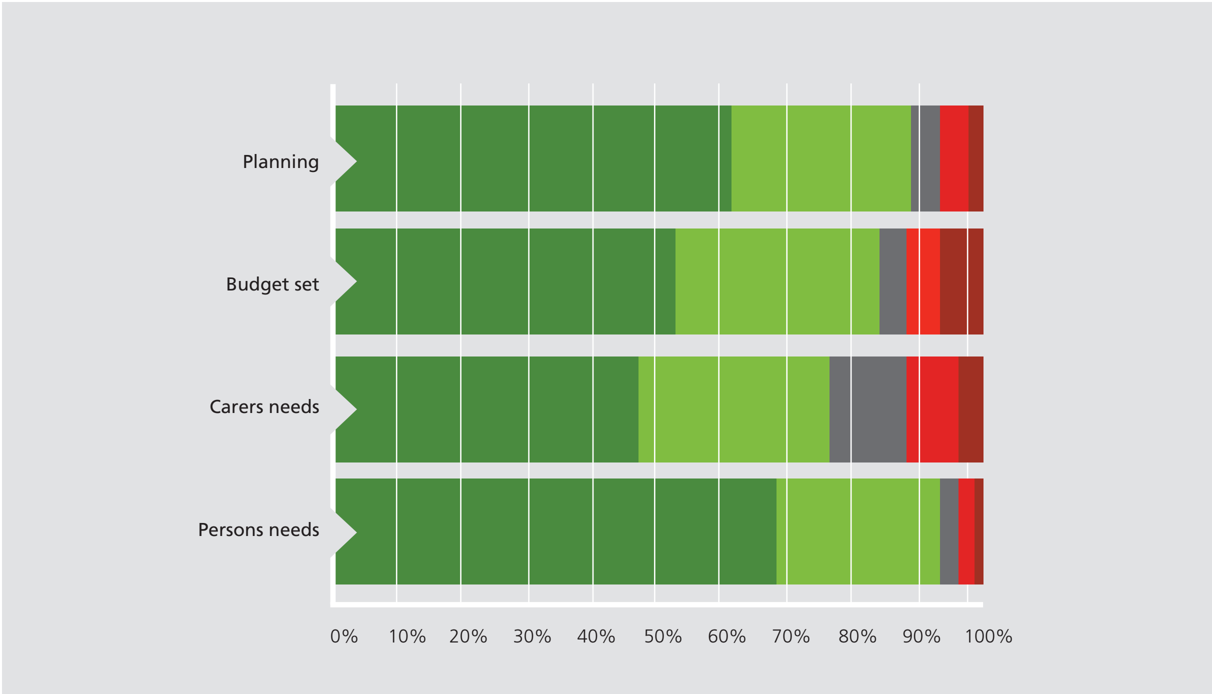
- Of the personal health budget holders being supported by carers, 35.0% had had their personal budget for less than a year, 43.2% had had their personal budget between one and three years, and 21.8 % had had their personal budget for over three years.
- Nearly three quarters (73.3%) of the people being supported by carers had received paid care or support before their personal health budget.
- Well over half of carers (60.3%) reported an amount for the personal health budget held by the person they were supporting.

Carers' experience of the personal health budget process

We asked carers questions about their experience of the personal health budget process. We asked whether carers felt their views were included when; the person's needs were assessed, their needs as a carer were assessed, the amount of money in the budget was set, and when the support plan was written.

Figure 15, below, shows at least three quarters of carers (76.5%) felt that their views were included mostly or very much in all aspects of the process we asked about. Of the four areas we asked about carers were most likely to say their views had not been included when the budget was set (12.1%).

FIGURE 15: Were carers' views included in the personal health budget?



Yes, very much   Yes, mostly   A little   No, not really   No, not at all

Have personal health budgets made a difference to carers' lives?

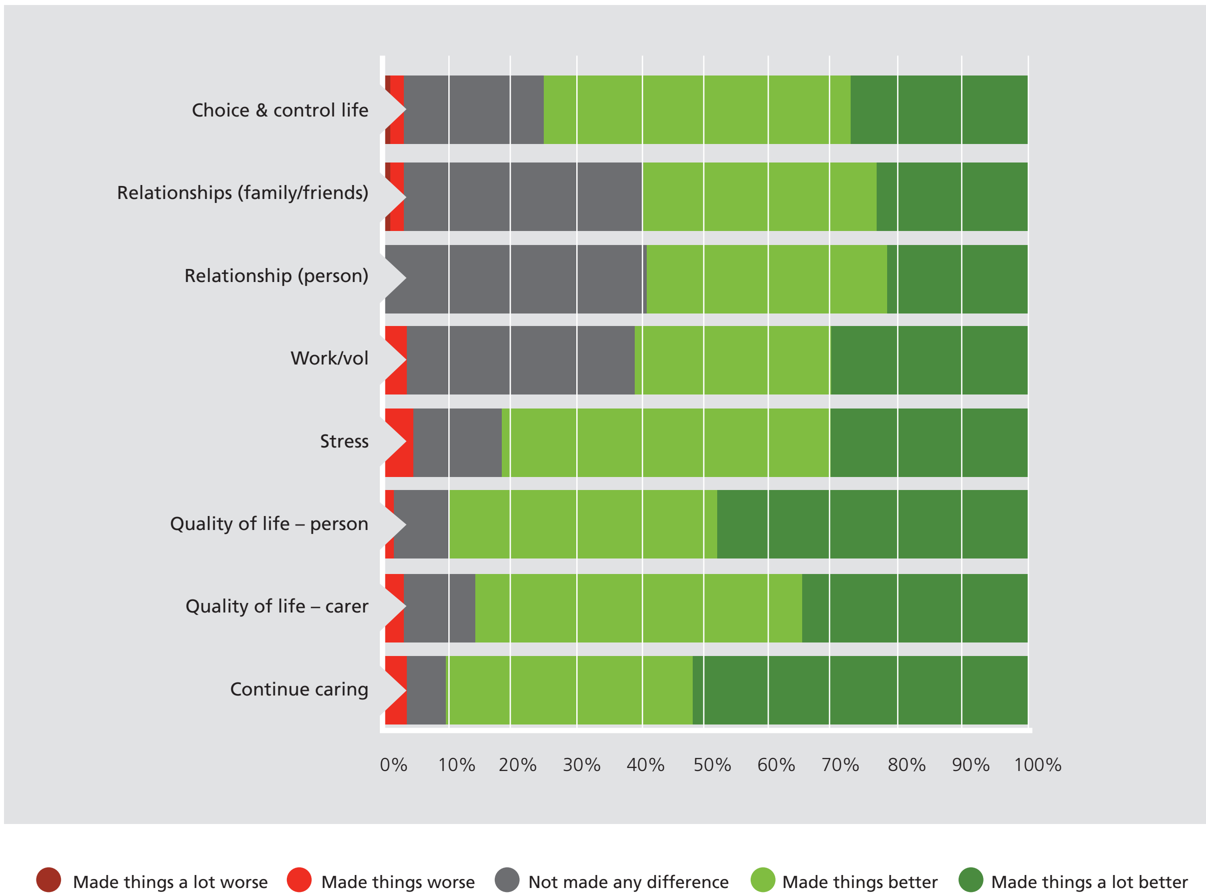
The POET survey asks carers whether the personal health budget has made a difference to eight aspects of their lives, and if so whether this difference has been positive or negative. Figure 16 summarises the findings for carers. Neither this POET personal health budget survey nor the most recent social care POET survey can claim to contain nationally representative samples, and because of this overall statistics concerning outcomes must be treated with caution. Carers were given an option to indicate if the area of life being asked about was not relevant to them. Percentages here are of those carers who said that area of life is relevant to them.

Over three quarters of carers said that having a personal health budget had made things better or a lot better in five of the eight aspects we asked about; day to day stress (82.3%), continue caring (91.7%), quality of life-carer (86.65%), quality of life-person (90.8%), and choice and control the carer has in life (76.1%).

More than half of carers said that the personal health budget had made things better or a lot better in three of the eight aspects we asked about; work or volunteering (61.8%); relationship-person (60.3%), relationships-family friends (60.5%).

Less than 3% of carers reported any areas of their lives getting worse as a result of personal health budgets.

FIGURE 16: Outcomes for carers



Made things a lot worse · Made things worse · Not made any difference · Made things better · Made things a lot better

What worked well, what didn't work well for carers and what would carers change

Carers were asked to comment about their experience of personal health budgets. We asked carers what worked well, what didn't work well and what specific changes they would make. Well over three quarters of carers commented on what had worked well (86.6%%),and nearly three quarters commented on what had not worked well (72.4%). A similar proportion made comments suggesting changes (74.5%).

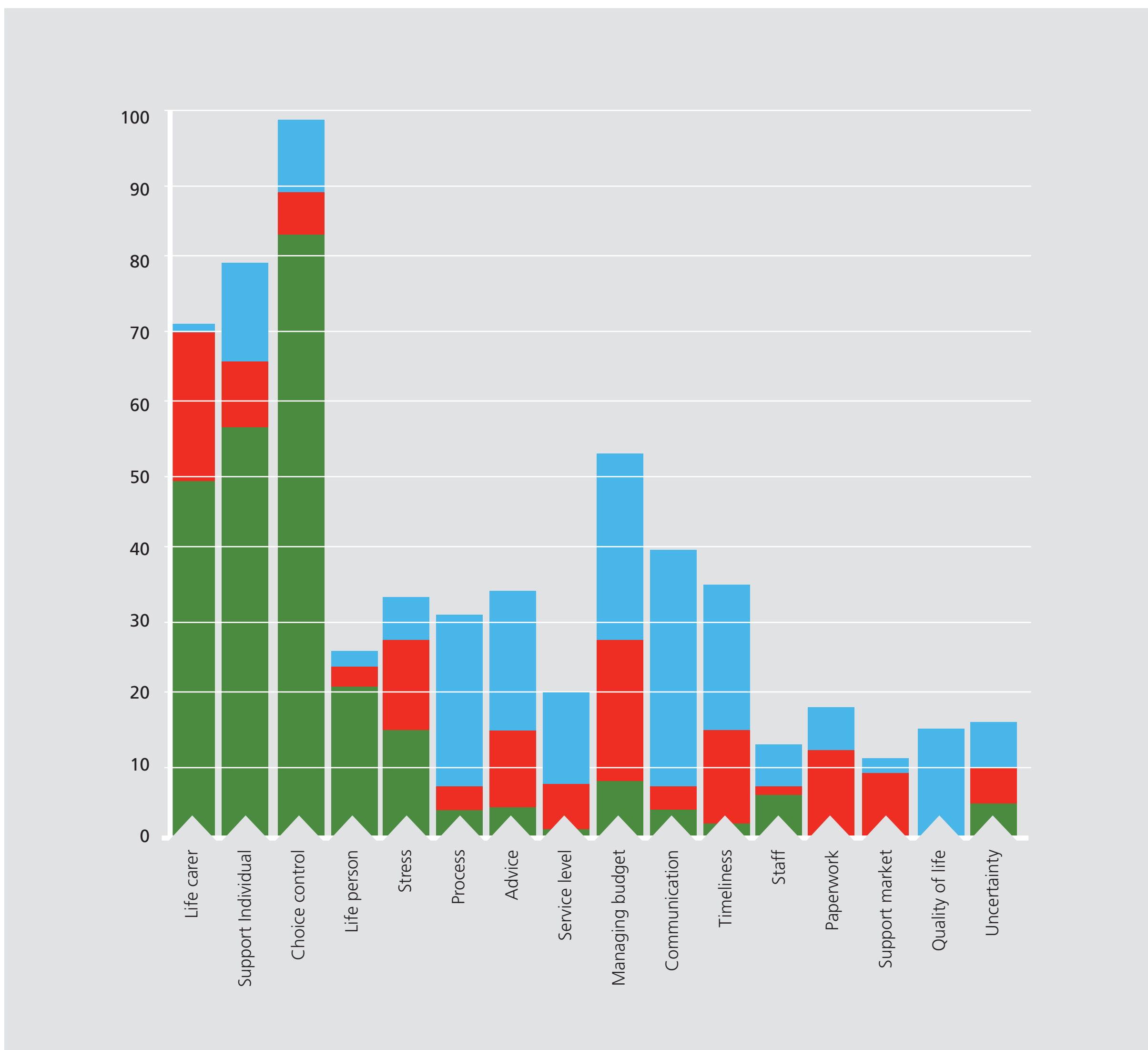
The length of response varied from a couple of words to several sentences, with most people providing just a single sentence. Responses tended to illustrate people's experience of the process of taking control of a personal health budget or the impact the personal budget had on their life.

In addition to their experience of personal health budgets people's comments covered a wide range of issues, in particular people described their own personal circumstances and the reason why they had a personal health budget and how important the support was to them.

As was the case with personal health budget holders, we used themes that had emerged from previous use of the POET to categorise the comments. Gathering and reviewing free text responses from carers by ongoing use of the POET has allowed us to identify several themes that commonly feature in the responses that carers provide. These themes were used by a small group of people who had experience of delivering personal health budgets to categorise and quantify the responses carers provided in this personal health budget survey. Responses that did not fit the established themes were then reviewed and categorised to identify areas that people talked about in this survey where they had not been mentioned previously. The following categories summarise the issues and themes carers wrote about in response to the three free text questions.

Life Carer	The impact of the personal health budget on the carer's life
Support/Treatment	The quality, nature, range, impact, and availability of support and treatment as a result of having a personal health budget including the degree of flexibility, choice.
Choice/Control	The degree of choice and control the personal health budget had allowed over treatment and support, and in other aspects of life.
Life Person	The impact of personal budgets on the life of the person they care for.
Stress/Worry	Emotional pressure, worry and stresses caused or relieved by the personal budget including responsibility of managing the budget. Stress and worry alleviated by the support provided through a personal budget.
Process	The experience of getting and controlling of a budget. In particular paper work involved in applying for or accounting for a budget.
Advice	The information, advice, guidance and support available to people taking control of a personal health budget. This includes clear policy, procedure and details of service options.
Funding/Service Level	The amount of money in the budget or service available as a result of having a budget.
Managing Budget	The experience of managing a personal health budget
Communication	The experience of communicating with staff, in particular difficulty accessing individuals. The impact of communication between organisations.
Timeliness	The length of time taken to get the personal health budget up and running.
Staff	The knowledge, understanding, attitudes of staff – mainly council staff responsible for referrals, assessments and support planning.
Paper work	The paperwork involved in applying for or accounting for a budget
Support Market	The availability of good providers and other service options
Quality of life	Life experiences affected by having a personal budget, including impact on emotional well-being, and ability to manage their health condition and on relationships with their family.
Employment/Setup	The responsibility and difficulty of recruiting managing and employing paid staff.
Uncertainty	Lack of confidence that the personal health budget will remain in place over time. Anxiety about the future.

FIGURE 17: Carers of personal health budget holders comments on; What worked well what didn't work well and what should change.



What factors are associated with positive outcomes for carers?

Figure 17 on page 45 shows how family carers feel the personal health budget has affected eight areas of their lives. In this section of the report we will ask three further questions:

1) Are there differences in the outcomes of the person's personal health budgets for family carers depending on the carer's age, gender or current health status?

2) Are there differences in the outcomes of the person's personal health budgets for family carers depending on the carer's caring circumstances?

3) Are aspects of personal health budget usage (previous local authority support, length of time with personal health budget, carer knowledge of the cost of personal health budget, carers feeling that their views are included in the support plan) associated with positive outcomes?

To address these questions, we checked whether there were associations between all the factors mentioned above and better outcomes on all the outcome indicators.

To make interpretation easier, we will express any associations found as odds ratios (for example, if a family carer knew the amount of the person's budget, what the odds are of them reporting a positive impact of their personal health budget compared to if they had not been helped to plan their personal budget). An odds ratio of 1 would mean that a positive impact was no more or less likely if people had been helped to plan or not. An odds ratio significantly less than 1 would mean that a positive impact was less likely if the family carer knew the amount of the budget (so an odds ratio of 0.5 would mean that carers were half as likely to report a positive impact if they knew the amount of the budget). An odds ratio significantly more than 1 would mean that a positive impact was more likely if the carer knew the amount of the person's budget (so an odds ratio of 2 would mean that carers were twice as likely to report a positive impact if they knew the amount of the person's budget). Odds ratios are a helpful way of showing how big an effect is, as well as whether it is statistically significant or not.

Because of the smaller numbers of family carers reporting the estimated amount of the person's budget, we did not conduct analyses of the relationship between the amount of people's budgets and outcomes for family carers.

However, it is important to say that we can only report associations between factors and outcomes, and if there is an association we cannot say that the process factor caused the outcome (for example, it could be that a third factor we didn't measure caused both the process factor and the outcome). It is important to bear this in mind, along with the relatively small numbers of people who responded, when interpreting the results we report below.

The tables following report the odds ratios for each factor against each outcome indicator. If an odds ratio shows that a factor is significantly associated with the outcome indicator (so the pattern of results has a less than 5% chance of being due to chance) than there is an asterisk next to the number.

All of these significant associations are reported in the text. Odds ratios significantly greater than 1 are shaded green; odds ratios significantly less than 1 are shaded red.

Table G, below, shows whether three personal factors (the family carer being less than 65 years old, female, or reporting themselves as in fair/bad/very bad health), and the person the family carer was supporting (son/daughter and spouse/partner, where there were sufficient numbers for statistical analysis), were associated with family carers reporting a positive impact of the person's personal health budget on eight areas of carers' lives.

There were relatively few associations. Carers aged 65 years or more were less than half as likely to report a positive impact of the personal health budget on their relationships with the personal budget holder or other family/friends.

Carers reporting themselves in poorer health were more than three times as likely to report a positive impact of the personal health budget on their capacity to continue caring.

Finally, carers caring for a son or daughter were twice as likely to report a positive impact of the personal health budget on their relationships with family and friends.

TABLE G: Personal factors and who the carer is caring for: Associations with positive outcomes for family carers

Outcome	Factors potentially associated with positive outcomes for family carers: Personal factors and relationship of the carer to the personal budget holder				
	Carer 65 years old or over	Carer female gender	Carer fair/bad/ very bad health	Caring for son/ daughter	Caring for spouse/ partner
Choice & control-carer life	0.73	0.95	1.34	1.64	1.09
Relationships family/friends	0.43*	1.02	0.79	2.00*	0.59
Relationship with PHB holder	0.46*	0.65	0.94	1.15	1.05
Work/Voluntary activity	0.49	1.51	0.82	1.30	0.82
Quality of life	0.71	0.85	1.43	1.43	1.11
QoL PHB holder	0.53	0.43	0.63	1.95	1.64
QoL carer	1.02	0.90	0.70	1.15	1.56
Continuing caring	1.26	0.66	3.53*	2.14	1.83

n/c=Odds ratio not calculable

Table H on page 49 shows potential associations between various aspects of the caring situation for the family carer and aspects of the personal health budget (having held a budget for over a year, whether the carer knows the amount of the budget) and positive outcomes for carers for eight outcome indicators.

Table H shows that whether carers caring for more than 50 hours per week or not was only associated with one outcome indicator; people caring for more than 50 hours per week were half as likely to report the personal health budget having a positive impact on their relationship with the person holding the budget. Carers living in the same house as the personal budget holder were at least twice as likely to report a positive impact of the person's budget on their the carer's quality of life and capacity to continue caring.

Table H also shows that carers were twice as likely to report a positive impact of the personal health budget on their levels of stress and worry if the person they were supporting had been getting service support before the budget.

If the person had been getting a personal health budget for longer than one year, carers were more than twice as likely to report a positive impact of the person's budget on carers' levels of stress and worry, and the quality of life of both the budget holder and the carer.

Finally, if carers knew the amount of the person's budget they were more likely to report positive impacts of the person's budget on four of the eight outcome indicators. Carers who knew the amount of the budget were at least twice as likely to report a positive impact of the budget on their capacity to engage in paid or voluntary work, on their capacity to continue caring and on their levels of stress and worry; and were more than four times as likely to report a positive impact on the choice and control that carers had over their lives.

TABLE H: Aspects of caring and the personal health budget: Associations with positive outcomes for carers

Outcome	Factors potentially associated with outcome: Aspects of caring and the personal health budget				
	Caring for 50+ hrs per week	Carer in same house as PHB holder	Person had support before PHB	PHB held for >1 year	Know amount of PHB
Choice & control-carer life	0.94	1.22	1.40	0.82	4.39*
Relationships family/friends	0.82	0.77	1.55	1.49	1.60
Relationship with PHB holder	0.50*	0.57	1.49	1.66	0.91
Work/ Voluntary activity	0.75	0.96	1.33	1.65	2.63*
Stress/worry	0.94	1.53	2.18*	2.05*	2.55*
QoL PHB holder	0.85	1.30	1.53	2.43*	0.89
QoL carer	1.84	2.40*	1.62	2.48*	2.04
Continuing caring	2.13	3.21*	1.71	1.30	2.87*

n/c=Odds ratio not calculable

Table I on page 50 shows potential associations between carers' perceptions of whether their views were fully included at four points in the personal health budget planning process and positive outcomes for carers across eight outcome indicators. The relatively small number of family carers reporting that their views were not fully included in various parts of the personal health budget process means that statistically significant odds ratios are unlikely.

However, carers who reported their views were fully included when the needs of the personal health budget holder were being assessed were more than twice as likely to report a positive impact of the person's budget on carers' levels of stress and worry.

Carers who reported that their views were fully included when their needs as carers were being assessed were more likely to report a positive impact of the person's budget on the carers' relationships with other family and friends, on work and voluntary activity, on carers' quality of life and on the choice and control that carers had their own lives.

Carers who reported that their views were fully included when the amount of the budget was being set were at least twice as likely to report a positive impact of the person's budget on carers' work and voluntary activity, on carers' quality of life and on the choice and control that carers had their own lives.

TABLE I: Views included in the planning process: Associations with positive outcomes for family carers

Outcome	Factors potentially associated with outcome: Views included in the PHB planning process			
	Views included when PHB holder needs assessed	Views included when carer needs assessed	Views included when budget amount was set	Views include when support plan written
Choice & control-carer life	1.95	2.59*	2.88*	1.92
Relationships family/ friends	1.35	1.85*	1.28	1.28
Relationship with PHB holder	1.54	1.34	1.35	1.04
Work/Voluntary activity	1.92	2.23*	2.66*	1.61
Stress/worry	2.10*	1.95	1.82	1.06
QoL PHB holder	1.43	1.52	1.41	1.09
QoL carer	2.18	2.63*	2.59*	1.19
Continuing caring	1.98	2.89	2.63	1.90

n/c=Odds ratio not calculable

APPENDIX1: EQUALITIES MONITORING INFORMATION

POET survey's respondents were asked a number of questions relating to their personal identity.

Gender	Response Rate	Male	Female
Carers	93.93%	27.16%	72.84%

Age	Response Rate	16-24%	25-34%	35-44	45-54%	55-64%	Over 65%
Personal Budget Recipient	89.07%	11.15%	11.15%	13.75%	14.13%	22.30%	27.51%
Carers	94.33%	0.00%	1.29%	13.30%	27.47%	30.90%	27.04%

Ethnicity	Response Rate	Any White	Mixed	Asian/ Asian British	Black/ Black British	Chinese
Personal Budget Recipient	85.76%	89.19%	2.32%	4.63%	3.09%	0.77%
Carers	89.88%	93.24%	1.80%	3.60%	0.90%	0.45%

Religion	Response Rate	B'hist	Christian	Hindu	Jewish	Muslim	Sikh	No religion	Any other religion
Personal Budget Recipient	83.77%	2.37%	62.45%	0.79%	0.00%	3.56%	0.79%	28.06%	1.98%
Carers	83.81%	0.48%	66.18%	0.97%	0.00%	3.38%	0.00%	28.99%	0.00%

Sexuality	Response Rate	Heterosexual	Other
Personal Budget Recipient	75.83%	93.89%	6.11%
Carers	87.85%	94.93%	5.07%

Think Local Act Personal

Think Local Act Personal (TLAP) is a national strategic partnership of more than 50 organisations committed to supporting the continued implementation of personalisation and community-based health, care and support.

web: www.thinklocalactpersonal.org.uk

email: thinklocalactpersonal@scie.org.uk

twitter: @tlap1