



# THE POET SURVEYS OF PERSONAL HEALTH BUDGET HOLDERS AND CARERS 2013

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## Thank you

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The authors are indebted to this group who made the work possible, however any errors of omission or interpretation, are wholly the responsibility of the authors.

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# Summary

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The Government has committed the NHS to rolling out personal health budgets across England. By April 2014 all clinical commissioning groups will need to be able to offer personal health budgets to people receiving NHS Continuing Healthcare, and by April 2015 everyone who could benefit will have the option of a personal health budget.

## The POET Surveys

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The POET (Personalisation Outcome Evaluation Tool) surveys for personal budget holders and for carers of personal budget holders in social care have been developed over several years as a way for personal budget holders and carers to report their experiences of personal budgets. The latest versions of the POET surveys for social care were adapted for this project to try and suit the circumstances of people using personal health budgets and their carers.

This survey included 9 sites which have focused on health and social care integration, including joint health and social care personal budgets. In total, 195 personal health budget holders and 117 carers across 12 sites completed the POET survey and gave their agreement for the information to be used.

## Major Findings

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For personal health budget holders:

- A vast majority of respondents were white (87.2%), with just over half of respondents being women (53.7%) and respondents represented a broad adult age range.
- Personal health budget holders reported a wide range of primary long-term conditions for which they held their budget, most commonly COPD/emphysema (14.5%), MS/MND (12.8%), a mental health condition (12.3%), learning disabilities (7.8%), stroke (5.6%) or tetraplegic conditions (5.6%).
- Compared to 2011 census data, personal budget holders reported their general health as much poorer than the general population in England. Less than a quarter (24.4%) of personal health budget holders reported their health as good or very good, compared to over three-quarters (79.4%) of the general population, and over a third (36.9%) of

personal health budget holders reported their health as bad or very bad compared to less than 10% (6.4%) of the general population.

#### In terms of personal health budget usage:

- People most commonly managed their personal health budget through direct payments paid to them (30.8%), followed by direct payments looked after by a broker (29.7%). Council or NHS-managed personal health budgets (13.3%), service provider-managed personal health budgets (12.3%) and direct payments looked by a family member or friend (11.3%) were less common, and 5.6% of people did not know how their personal health budget was managed.
- There were no gender or age differences in usage of any type of personal health budget, or any differences according to people's self-reported health.
- A substantial majority of personal health budget holders (80.0%) reported having been told their weekly support costs. For the 117 people who could provide an estimate of the annual cost of their personal health budget the median estimated value of people's personal health budgets was £2,340 per year, although there was wide variation in annual costs reported by respondents.
- There were no statistically significant differences in the estimated annual amount of people's personal health budgets by gender, age or self-reported health status, although people holding some form of direct payment had more expensive budgets (median £9,685 per year) than people with managed budgets (median £834 per year).

#### In terms of support to people holding a personal health budget:

- Just over half of people got help in planning personal health budgets from the NHS (52.3%), around a quarter of people got help in planning from family/friends (28.7%) or help from someone independent of the NHS or the council (22.6%), and just over one tenth of people got help to support from the council (13.3%) or did their planning themselves without help (11.8%).
- A vast majority of respondents (93.6%) reported that their views were very much or mostly included in their support plan.
- More than 60% of respondents felt that the NHS or other main support organisation had made it easy or very easy to know how to spend their personal health budget (61.6%) or to be in control of how their personal budget was spent (61.0%).
- Over half of respondents felt that the NHS or other main support organisation had made it easy or very easy to assess their needs (57.6%), complain (55.2%), plan and manage their support (55.1%), get the support they wanted (53.8%) or get information/advice (52.9%).
- Less than half of respondents reported that it was made easy or very easy for them to choose their services (45.5%) or change their support (44.9%).
- Substantial minorities of people (between 13.8% and 21.5%) reported that their NHS or other main support organisation had made it difficult or very difficult in each aspect of the personal health budgets process.

### In terms of the impact (or not) of personal health budgets on people's lives:

- Over 70% of personal health budget holders reported their budget having a positive impact on their independence (72.6%).
- Over 60% of personal health budget holders reported their budget having a positive impact on their physical health (68.8%), getting the support they wanted (68.3%), being supported with dignity and respect (67.9%), being in control of their support (67.7%), being in control over the important things in life (67.2%), and on their mental wellbeing (63.9%).
- Over 50% of personal health budget holders reported their budget having a positive impact on the long-term condition for which they held the budget (59.4%), feeling safe in and outside the home (58.2%), their relationships with people paid to support them (53.1%), and their relationships with members of their family (50.8%).
- Fewer personal health budget holders reported a positive impact of their budget on their relationships with friends (41.6%) or choosing where and with whom they lived (34.3%). Very few people reported a positive impact on volunteering (17.3%) or getting and keeping a paid job (12.3%). In all these areas of life most people reported their personal health budget making no difference.
- Small numbers of people (between 1.7% and 4.9%) reported their personal health budget having a negative impact on any of these 15 aspects of people's lives.

- A big majority of personal health budget holders (82.6%) felt confident or very confident that their needs would be met with their personal health budget, with the remainder (17.4%) undecided; no-one reported feeling unconfident or very unconfident that their needs would be met.
- Factors robustly associated with positive outcomes for personal health budget holders included: holding the personal health budget in the form of a direct payment paid to family/friends; knowing the amount of the personal health budget; having help to plan from family/friends; feeling that their views were fully included in their support plan; and the NHS or other main support organisation making most aspects of the personal health budget process easier.

### For carers of people holding personal health budgets:

- Most respondents were white (91.5%) and women (70.2%), with the vast majority aged 45 or over (87.1%).
- Just over a quarter of carers (27.7%) reported themselves to have a disability, most commonly a physical disability (12.0%) and/or a longstanding illness/health problem (11.1%).
- Carers reported their general health somewhere between that of the general population in England and that of the people they were supporting. Over half of carers (54.8%) reported their health as good or very good and almost 10% of carers (9.5%) reported their health as bad or very bad.

- Carers were most commonly caring for a partner/spouse (43.6%), followed by an older family member (usually a parent; 26.5%) then a grown-up son or daughter (20.5%), with a small proportion of carers supporting someone else (e.g. a friend or neighbour; 6.0%).
- Over three quarters of carers (76.3%) were living in the same house as the person they were caring for, and a majority of carers (59.0%) were spending more than 50 hours per week caring.

**In terms of carers' views of the personal health budget held by the person they were supporting:**

- Over three quarters of carers (79.8%) knew the amount of the personal health budget held by the person they were supporting.
- Less than a quarter of carers (22.2%) reported that they were receiving a carers' personal budget, and very few carers (2.8%) reported that they were receiving their own personal budget for their own needs.
- The vast majority of carers (86.5%) felt that their views were fully included in the support plan of the person they were supporting.
- Almost half of carers (48.2%) felt that the personal health budget process as a whole was very easy or easy, but almost a quarter of carers (24.1%) felt that the personal health budget process was hard or very hard.

**In terms of the impact on the carer of the personal health budget held by the person they were supporting:**

- Over 60% of carers reported a positive impact of personal health budgets on their own quality of life (70.2%), support for them to continue caring (67.6%) and their finances (60.2%).

- Between 50% and 60% of carers reported a positive impact of personal health budgets on their choice and control over their own lives (58.4%), their relationships with people paid to support the budget holder (54.2%) and their physical and mental wellbeing (53.9% vs 52.9%).
- For another three outcome domains for carers, carers were relatively evenly split on whether personal health budgets held by the person they care for had had a positive impact or made no difference in the areas of the carer's social life (42.2% improved, 50.5% no difference), and the carer's relationships with the person cared for (47.5% improved, 42.1% no difference) and other family/friends (46.0% improved, 49.6% no difference).
- Most carers (72.0%) reported that personal health budgets had made no impact on their own capacity to get and keep a paid job.
- Less than 10% of carers reported any areas of their lives getting worse as a result of personal health budgets.
- Factors robustly associated with positive outcomes for carers included: carers knowing the amount of the personal health budget for the person they are supporting; carers feeling that their views were fully included in the support plan for the person's personal health budget; and carers having a positive experience of the personal health budget process.

# Background

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The Government has committed the NHS to rolling out personal health budgets across England. By March 2014 all clinical commissioning groups will need to be able to offer personal health budgets to people receiving NHS Continuing Healthcare, and by March 2015 everyone who could benefit will have the option of a personal health budget.

Following a successful pilot programme, NHS England is putting in place a delivery support programme which is available to all 211 CCGs. More information about the personal health budgets programme is available at [www.personalhealthbudgets.england.nhs.uk](http://www.personalhealthbudgets.england.nhs.uk)

Alongside this, a number of leading sites have committed to rolling out personal health budgets more widely – for example to people who have long term conditions, and people with mental health problems. These sites are also offering integrated health and social care budgets. The sites have worked with In Control and Lancaster University to develop a version of the POET tool in the NHS to tell us how well personal health budgets and integrated budgets are working.

This survey looked at the experience of people who have a personal health budget and their families in the first six months following the end of the pilot programme.

## Development of POET survey tools

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Tools for the on-going, low cost and routine monitoring of the processes and outcomes associated with personal budgets in social care have been in continuous development for approximately 10 years, involving a collaboration between In Control, Lancaster University and local authorities. In 2003 In Control and Lancaster University came together to evaluate a small pilot that introduced personal budgets for 60 people with learning disabilities living in 5 local authority areas. Since then two further evaluation reports have been produced accompanying the introduction of personalised budgets in social care on an ever increasing scale, including the biggest social care survey to date due to be published at approximately the same time as this report.<sup>1</sup>

<sup>1</sup> Poll, C., Duffy, S., Hatton, C., Sanderson, H. & Routledge, M. (2006). *A report on in Control's first phase 2003-2005*. London: In Control Publications. Hatton, C. & Waters, J. (2008). *Evaluation report: Phase Two of in Control's work 2005-2007*. In C. Poll and S. Duffy (eds.), *A report on in Control's second phase: evaluation and learning 2005-2007* (pp. 5-25). London: in Control Publications. Hatton, C. & Waters, J. (2011). *The National Personal Budget Survey – June 2011. Think Local Act Personal*: London.

The POET survey tools in social care have emerged over time from this work and have undergone a number of iterations, each version developed from the last in response to feedback from key stakeholders including people completing and implementing the survey. In this report, we describe a project using adapted versions of the social care POET tool with personal health budget holders and their carers. In consultation with a range of people implementing personal health budgets, the POET survey tools were adapted to try and suit the circumstances of personal health budget holders and their carers.

The POET survey tools for this project gather views and experiences from personal health budget holders, their (mainly family) carers and paid staff, although only information from personal health budget holders and carers is provided in this report. The POET tool is designed to measure how well organisations are managing to implement personal health budgets and to what effect. Specific questions investigate people's experience of the 'personal health budget process' and the impact of the personal health budget on their everyday life.

The intention has been to provide organisations with a way of measuring and understanding their performance as it is understood by local people who are looking to them for help, rather than by setting defined standards for time, task and cost against which performance is judged, as has traditionally been the case. It is this shift to a focus on 'outcomes' and 'experience of process' that distinguishes the POET survey tool.

Conceptually the POET tools have been designed to generate 'practice-based evidence'.<sup>2</sup> Practice-based evidence is produced by pooling information on routine practice across a range of localities to produce datasets big enough to address questions that could not be investigated using local information alone. In the context of the social care POET, pooling together such information allows us to investigate questions such as: Are different types of personal budget associated with different experiences for personal budget holders and carers? Do people with different needs and carers in different circumstances have different experiences of personal budgets? Which factors are associated with more positive (and less positive) outcomes for personal budget holders and carers? While the implementation of personal health budgets is at an earlier stage and the number of respondents to the survey is corresponding smaller, we still hope to address some of these questions for personal health budget holders and carers.

Practice-based evidence is designed to complement the large-scale research which is also required to generate the evidence crucial for guiding best practice. Compared to such large-scale research projects, practice-based evidence projects are lower cost, have a relatively low impact on people involved, are relatively quick to conduct and collect (and repeat), are closer to the reality of how services are routinely working (or not working) for people, and have feedback loops back to practice built into the process.

<sup>2</sup> Barkham, M. & Mellor-Clark, J. (2003). Bridging evidence-based practice and practice-based evidence: Developing a rigorous and relevant knowledge for the psychological therapies. *Clinical Psychology & Psychotherapy*, 10, 319-327.

Some of these advantages are also limitations compared to large-scale research projects. For example practice-based evidence projects are dependent on the voluntary participation of interested services and people, making it more difficult to gain groups of participants that are nationally representative. In addition, because practice-based evidence projects are designed to be relatively easy to fit within routine practice, the range and depth of information collected is not as extensive as the information collected during large-scale research projects. Both large-scale research projects and practice-based evidence projects are needed to provide the information needed to continuously improve practice.

## The POET personal health budgets survey

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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
  - What personal health budgets people are using 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

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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 contained the following questions, including:

- 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 how confident personal health budget holders are that their budget will meet their needs.
- Information about whether people answered the questions on their own or had help.
- Equalities monitoring questions (gender, age, disability, ethnicity, religion, sexual orientation).
- Space for people to write in their opinions on personal budgets and the survey questionnaire.

## The survey for carers of personal health budget holders

The POET survey for carers contained the following questions, including:

- 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, whether the carer is also getting any personal budget or direct payment support, and whether the carer's views were included in the support planning process.
- Information about whether the personal health budget holder's budget has made a difference (either positive or negative) across 10 aspects of the carer's life.
- Information on carers' self-rated assessment of their current general health.
- Information about how confident carers are that personal health budgets will meet the needs of the person they are supporting.
- Equalities monitoring questions (gender, age, disability, ethnicity, religion, sexual orientation).
- Space for people to write in their opinions on personal budgets and the survey questionnaire.

## Gaining information from personal health budget holders and carers

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Because the POET surveys were designed for people to evaluate their experiences of existing personal health budgets, the surveys were clearly service evaluation rather than research according to guidance from the National Research Ethics Service<sup>3</sup> and therefore did not require Research Ethics Committee approval.

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

In total, 195 personal health budget holders completed the POET survey and gave their agreement for the information to be used, across 12 sites. Of these, there were returns from 10 or fewer people in four sites, 11-20 people in four sites, 21-30 people in three sites, and 31-40 people in one site. In terms of the type of organisation from which personal health budget holders said they received their budget, 184 people provided a response: 102 personal health budget holders said they got their budget from a PCT, 45 said they got their budget from an NHS Trust and 25 from a local authority, with small numbers mentioning their local team or another type of organisation or organisational partnership.

In total, 117 carers had completed the POET survey and given their agreement for the

information to be used, across 12 sites. Of these, there were returns from 10 or fewer carers in seven sites, 11-20 people in four sites, and 21-30 people in one site. In terms of the type of organisation from which carers said the person they were caring for received their budget, 110 carers provided a response: 61 carers said the budget was from a PCT, 30 said the budget was from an NHS Trust and 16 from a local authority, with three carers mentioning their local team or another type of organisation or organisational partnership.

In both personal health budget holder and carer versions, responses to most of the POET survey questions were recorded numerically and converted into 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  $p<0.05$ .

For the open questions asking if people wanted to write in anything about their experiences of personal health budgets, we used a complete list of what people wrote to develop a set of themes summarising people's experiences from what they had written. Each quote was then examined and assigned to one or more themes depending on what the person had written – for most comments a judgement was also made on whether the comment was mainly positive, negative or neutral in relation to the theme. This was done separately for personal health budget holders and carers.

<sup>3</sup> National Research Ethics Service <http://www.nres.npsa.nhs.uk/applications/is-your-project-research/>

# Findings – Personal Health Budget Holders

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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 or don't make to people's lives?
- What factors are associated with better outcomes for personal health budget holders?

## Who responded to the POET survey?

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As mentioned earlier, a total of 195 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, the totals reported throughout the report are unlikely to add up to this overall total.

Equalities monitoring information is presented in detail in Appendix 1. In outline, this information shows:

- Just over half of personal health budget holders (51.9%) answered the POET survey on their own, with almost a third (29.7%) of people answering the survey in a meeting or interview and fewer (18.4%) answering the questions with help from someone else. No surveys were returned saying that the survey questions had been mostly answered by someone other than the personal health budget holder.
- Just over half of respondents (53.7%) were women.
- In terms of age, 29.4% of personal health budget holders were aged 16-44 years, 39.6% were aged 45-64 years, and 30.5% were aged 65 years or over.
- A vast majority of respondents were white (87.2%), with 6.2% of respondents not giving this information and little representation from any other ethnic groups.
- Over half of respondents were Christian (55.9%), with 12.8% of respondents not giving this information and over a quarter (27.2%) reporting themselves to have no religion.
- A large majority of respondents reported themselves to be heterosexual/straight (82.1%), with 15.4% of respondents not giving this information.

The POET survey for personal health budget holders also asked people to give the name of the long-term condition(s) for which they were getting a personal health budget. There was a wide variety of responses, with 51 different conditions reported as the person's primary long-term condition by the 179 respondents who answered this question. Conditions named by five or more respondents were:

- COPD/emphysema (26 respondents; 14.5%)
- MS/MND (23 respondents; 12.8%)
- Mental health condition, including depression and psychosis (22 respondents; 12.3%)
- Learning disabilities, including Down syndrome and Fragile X (14 respondents; 7.8%)
- Stroke (10 respondents; 5.6%)
- Tetraplegic conditions (10 respondents; 5.6%)
- Pain (8 respondents; 4.5%)
- Arthritis (8 respondents; 4.5%)
- Dementia (6 respondents; 3.4%).

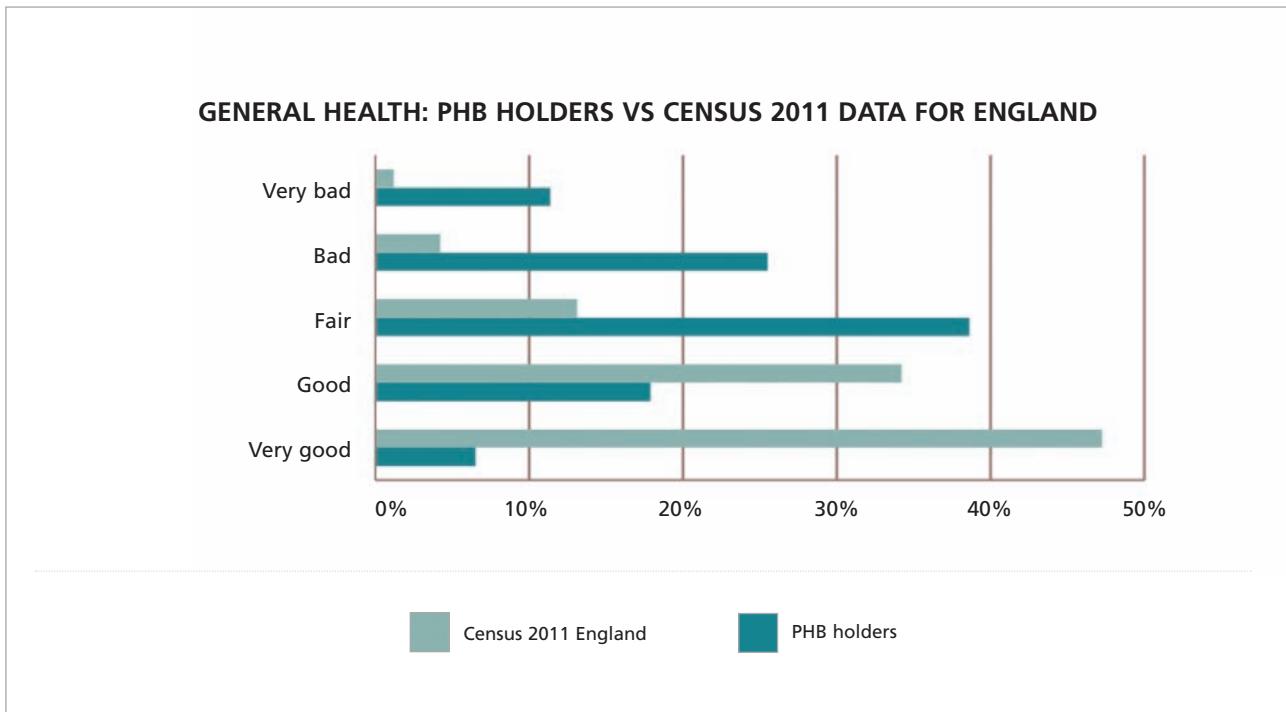
The POET survey also asks personal health budget holders about whether they consider themselves to have a disability, and if so the nature of their disability, with people able to endorse as many types as were relevant to them. A large majority of respondents (81.0%) reported themselves to have a disability. In terms of specific types of disability:

- Just over half of respondents (98 people; 50.3%) reported themselves to have a physical disability.
- Just under half (94 people; 48.2%) reported themselves to have a long-standing illness/health condition.
- Mental health conditions reported as a disability (23 people; 11.8%), learning disabilities (21 people; 10.8%) and sensory impairments (11 people; 5.6%) were less common.

Because of the diversity of long-term conditions reported by respondents, the limited size of the sample, and the fact that certain sites focused on people with particular conditions, unfortunately it was not possible to conduct analyses of the data comparing across different long-term conditions as any differences across conditions would be difficult to interpret.

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. Less than a quarter (24.4%) of personal health budget holders reported their health as good or very good, compared to over three-quarters (79.4%) of the general population, and over a third (36.9%) of personal health budget holders reported their health as bad or very bad compared to less than 10% (6.4%) of the general population.

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



## How are people using personal health budgets?

The POET survey asks personal health budget holders several questions about how they are using 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 (aged 16-64 years versus 65 years or older) and self-reported health status (very good/good versus fair versus bad/very bad).

## How do people manage their personal health budgets?

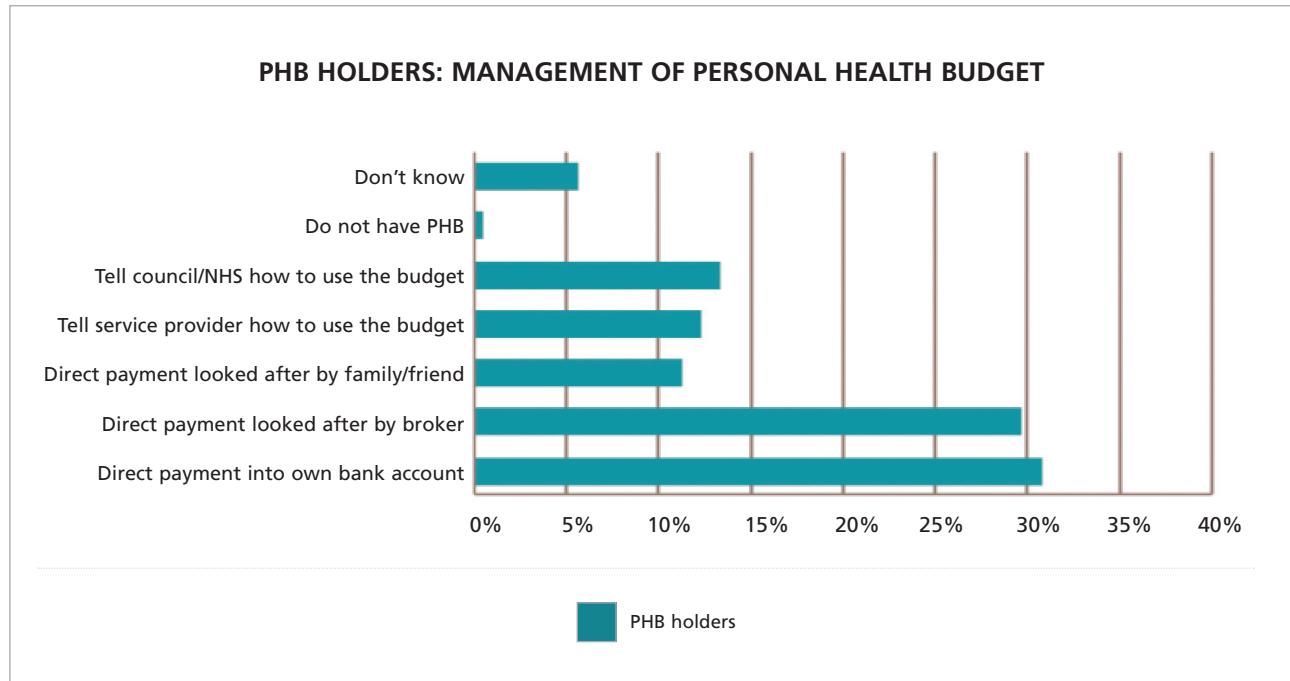
Figure 2 shows the different ways that people managed their personal health budgets.

Overall, in this sample of POET survey respondents, people most commonly managed their personal health budget through direct payments paid to them (30.8%), followed by direct payments looked after by a

broker (29.7%). Council or NHS-managed personal health budgets (13.3%), service provider-managed personal health budgets (12.3%) and direct payments looked by a family member or friend (11.3%) were less common, and 5.6% of people did not know how their personal health budget was managed.

There were no gender<sup>4</sup> or age<sup>5</sup> differences in usage of any type of personal health budget, or any differences according to people's self-reported health.<sup>6</sup>

**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 personal health budgets. Overall, almost half (47.8%) of respondents had held their personal budget for less than a year, over a third (37.7%) for between one and three years, and relatively few (13.6%) for more than three years.

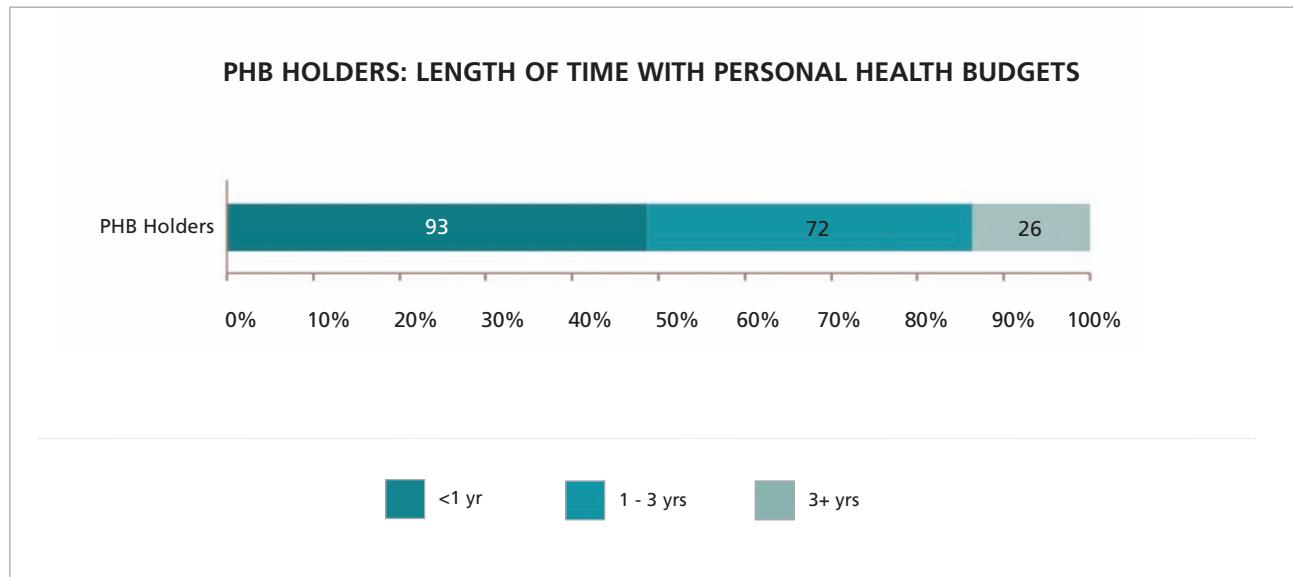
<sup>4</sup> DP into own bank account Fisher's exact  $p=0.44$ ; DP looked after by broker Fisher's exact  $p=0.43$ ; DP looked after by family/friend Fisher's exact  $p=0.82$ ; Service provider-managed Fisher's exact  $p=1.00$ ; Council/NHS-managed Fisher's exact  $p=0.20$

<sup>5</sup> DP into own bank account Fisher's exact  $p=0.61$ ; DP looked after by broker Fisher's exact  $p=0.17$ ; DP looked after by family/friend Fisher's exact  $p=0.47$ ; Service provider-managed Fisher's exact  $p=0.09$ ; Council/NHS-managed Fisher's exact  $p=1.00$

<sup>6</sup> Chi-square=2.1,  $df=2$ ,  $p=0.35$

There were no differences in the length of time people had held a personal health budget by gender,<sup>7</sup> age,<sup>8</sup> self-reported health status<sup>9</sup> or the type of personal health budget people held.<sup>10</sup>

**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 local authority support before they got their personal health budget. Overall, just under half (45.7%) 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,<sup>11</sup> age,<sup>12</sup> self-reported health status<sup>13</sup> or the type of personal health budget people held.<sup>14</sup>

7 Chi-square=3.1, df=2, p=0.21

8 Chi-square=3.6, df=2, p=0.17

9 Chi-square=9.3, df=4, p=0.06

10 Chi-square=12.5, df=8, p=0.13

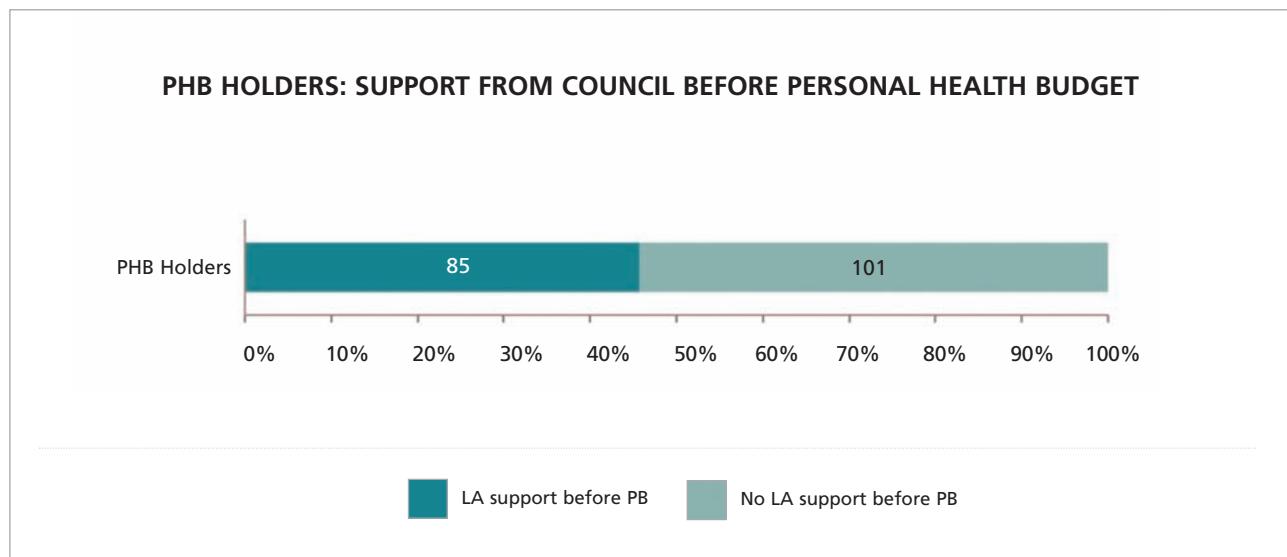
11 Fisher's exact p=1.00

12 Fisher's exact p=0.42

13 Chi-square=0.5, df=2, p=0.78

14 Chi-square=3.5, df=4, p=0.47

**Figure 4: Previous social care support before the personal health budget**



## The cost of personal budgets

The POET survey asked personal health budget holders whether they were told the weekly amount of their personal health budget and whether they could provide an estimate of the amount expressed annually.

Figure 5 shows that overall a substantial majority of personal health budget holders (80.0%) reported having been told their weekly support costs. There were no statistically significant differences in whether people had been told their support costs or not by gender,<sup>15</sup> age,<sup>16</sup> self-reported health status<sup>17</sup> or type of personal budget.<sup>18</sup>

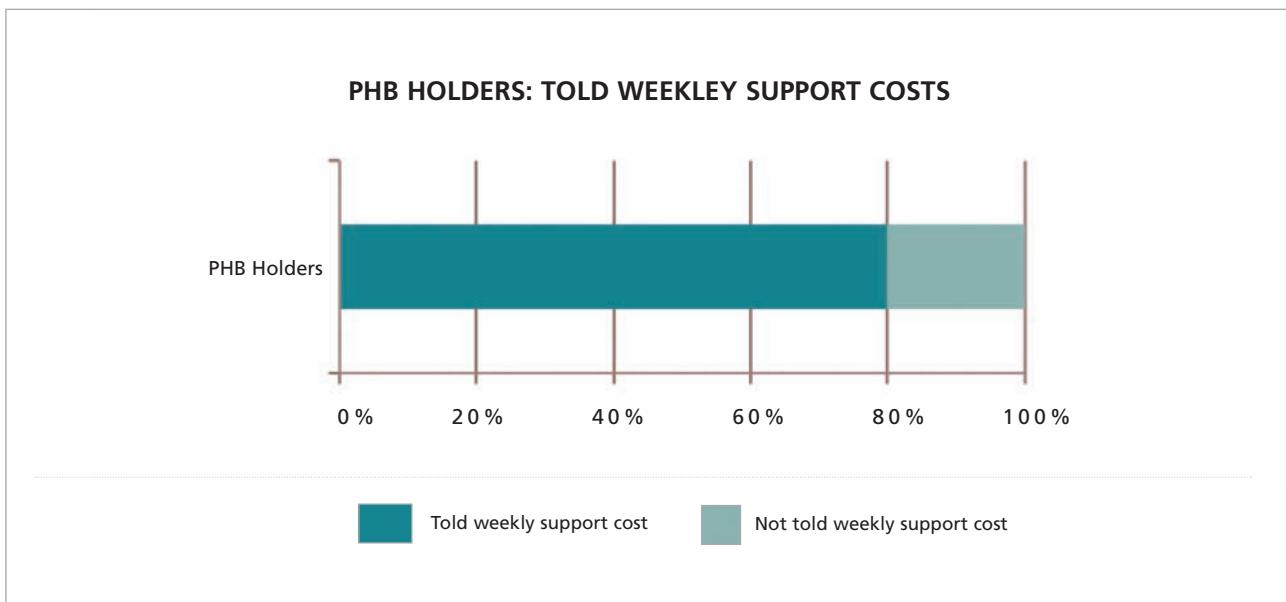
<sup>15</sup> Fisher's exact  $p=0.35$

<sup>16</sup> Fisher's exact  $p=0.69$

<sup>17</sup> Chi-square=0.02,  $df=2$ ,  $p=0.99$

<sup>18</sup> Chi-square=5.5,  $df=4$ ,  $p=0.24$

**Figure 5: Personal health budget holders reporting being told their weekly support costs**



For the 117 people who could provide an estimate of the annual cost of their personal health budget, Figure 6 summarises these estimates. The overall, the median estimated value of people's personal health budgets was £2,340 per year, although this median does not show the wide variation in annual costs reported by respondents. Almost half of the 117 respondents (47.9%) estimated the cost of their personal health budget as £2,000 per year or less. At the opposite end of the cost spectrum, 16.3% estimated the cost of their personal health budget as £50,000 per year or more.

There were no statistically significant differences in the estimated annual amount of people's personal health budgets by gender,<sup>19</sup> age<sup>20</sup> or self-reported health status.<sup>21</sup>

Due to the restricted numbers of people knowing their personal budget, for this analysis we collapsed type of budget into direct payment (to the person, looked after by a broker, looked after by family/friend) versus managed (service provider managed, council/NHS managed). Overall, people holding direct payments had more expensive budgets (median £9,685 per year) than people with managed budgets (median £834 per year), a statistically significant difference<sup>22</sup>

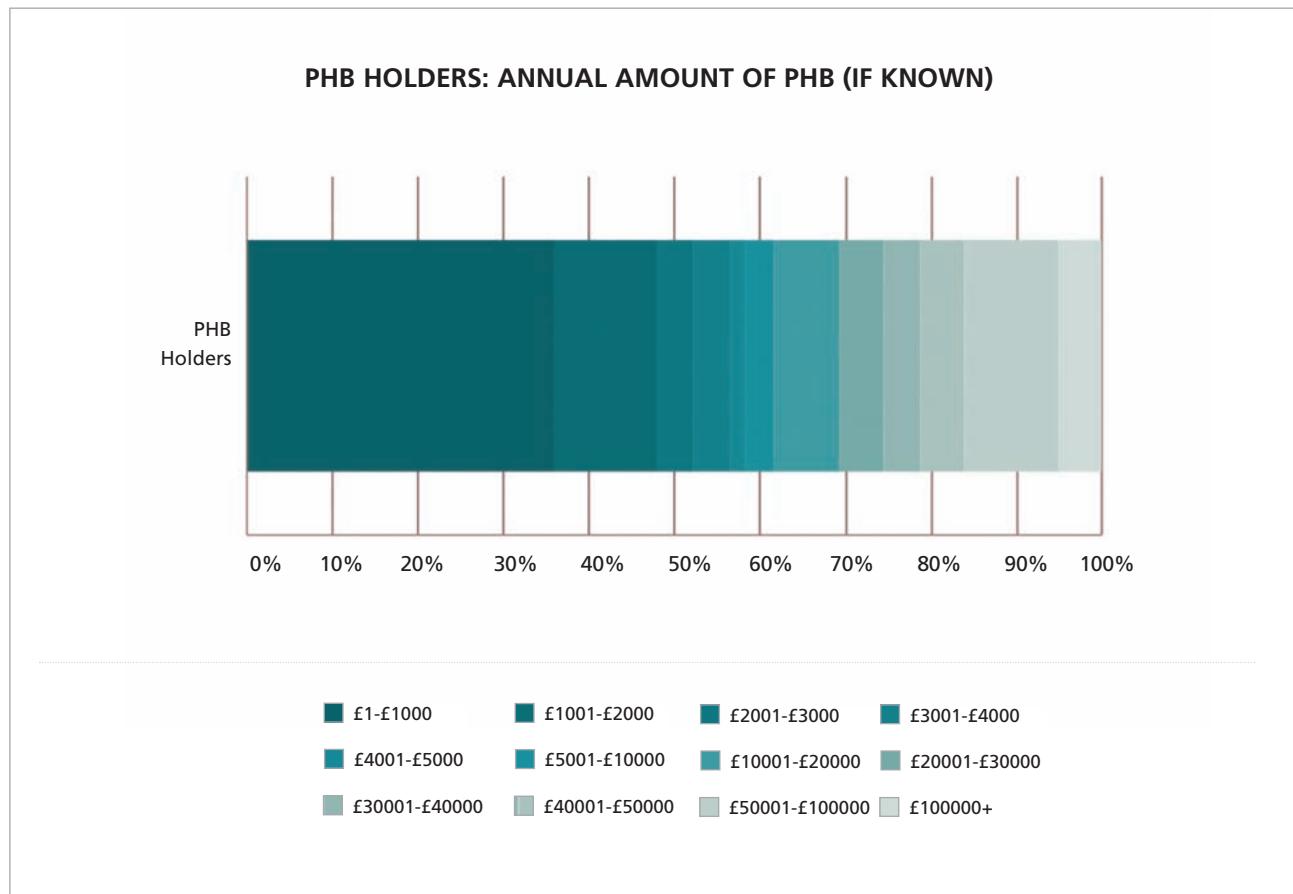
19 Mann Whitney  $U=1635.5$ ,  $n=116$ ,  $p=0.87$

20 Mann Whitney  $U=1252.5$ ,  $df=113$ ,  $p=0.67$

21 Kruskal Wallis chi-square=1.0,  $df=2$ ,  $p=0.60$

22 Mann Whitney  $U=537$ ,  $n=110$ ,  $p=0.001$

**Figure 6: Estimated annual amount of personal health budgets**



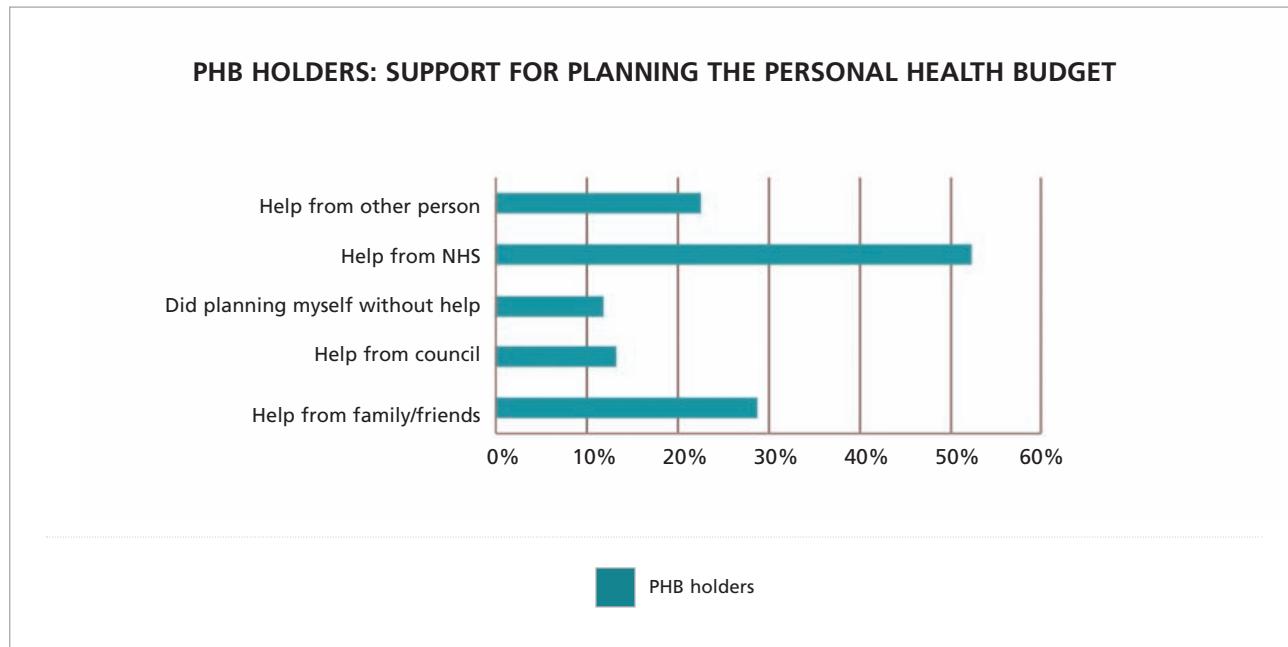
## Support for planning personal health budgets

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 the personal health budget support plan.

Figure 7 shows how many people used various sources of support in planning their personal health budget. Overall, just over half of people got help in planning personal health budgets from the NHS (52.3%), around a quarter of people got help in planning from family/friends (28.7%) or help from someone independent of the NHS or the council (22.6%), and just over one tenth of people got help or support from the council (13.3%) or did their planning themselves without help (11.8%).

There were no differences across type of personal health budget in the proportion of people getting help to plan from the NHS<sup>23</sup> or the council,<sup>24</sup> or who did their planning themselves without any help.<sup>25</sup> People with a direct payment looked after by a family member or friend were more likely than people holding other types of personal health budgets to get help or support from family/friends,<sup>26</sup> and people with a direct payment looked after by a broker were more likely to get support to plan from someone independent of the NHS or council.<sup>27</sup>

**Figure 7: Support for planning personal health budgets**



Finally, the POET survey asked respondents whether their views were included in their support plan. Overall a vast majority of respondents (93.6%) reported that their views were very much or mostly included in their support plan (see Figure 8). These highly positive ratings meant that there were too few negative ratings to calculate statistical tests comparing people's experiences across different types of personal health budget.

23 Chi-square=6.7, df=4, p=0.15

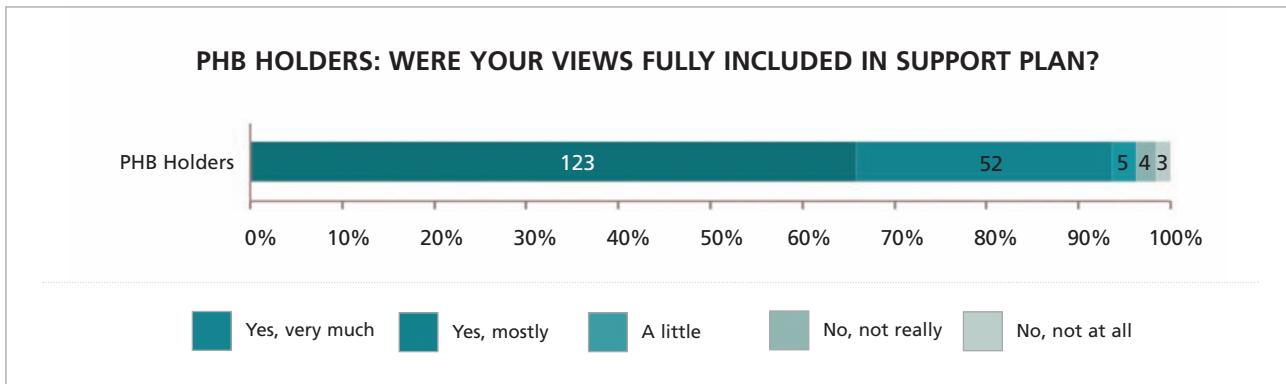
24 Chi-square=4.2, df=4, p=0.38

25 Chi-square=8.0, df=4, p=0.09

26 Chi-square=36.8, df=4, p<0.001

27 Chi-square=15.5, df=4, p=0.004

**Figure 8: Were people's views included in the support plan for their personal health budget?**



## The role of the NHS or other main support organisation in supporting personal health budgets

As Figure 9 reports, the POET survey asked several questions to personal health budget holders about whether the NHS or other main support organisation was helpful or not throughout various aspects of the personal health budgets process. As many people's budgets were of relatively short duration and/or made as one-off payments, it is possible that not all of these questions would have been relevant to all respondents at the point in time they completed the survey.

As Figure 9 shows, overall more than 60% of respondents felt that the NHS or other main support organisation had made it easy or very easy to know how to spend their personal health budget (61.6% of 190 respondents) or to be in control of how their personal budget was spent (61.0% of 187 respondents). Over half of respondents felt that the NHS or other main support organisation had made it easy or very easy to assess their needs (57.6% of 184 respondents), complain (55.2% of 181 respondents), plan and manage their support (55.1% of 185 respondents), get the support they wanted (53.8% of 184 respondents) or get information/advice (52.9% of 189 respondents).

Less than half of respondents reported that it was made easy or very easy for them to choose their services (45.5% of 178 respondents) or change their support (44.9% of 167 respondents).

Overall, substantial minorities of people (between 13.8% and 21.5%) reported that their NHS or other main support organisation had made it difficult or very difficult in each aspect of the personal health budgets process.

To investigate potential differences across the types of main organisations supporting people, we collapsed the organisations into three types (PCT, NHS Trust, council) and collapsed the responses to each easy/difficult question into two categories (Very easy/easy vs Not easy or Difficult/Very difficult). There were no differences according to type of support organisation in whether people found it easy to get information/advice,<sup>28</sup> assess their needs,<sup>29</sup> know how to spend their budget,<sup>30</sup> get the support they wanted,<sup>31</sup> change their support,<sup>32</sup> choose services<sup>33</sup> or complain.<sup>34</sup> People felt that councils made it less easy than PCTs or NHS Trusts for people to be in control of how the budget was spent,<sup>35</sup> or to plan and manage their support (with PCTs also being most likely to make this easy).<sup>36</sup>

There were no differences across type of personal health budget in whether people felt their main support organisation had made any aspect of the personal health budget process easy.<sup>37</sup>

28 Chi-square=5.2, df=2, p=0.08

29 Chi-square=4.4, df=2, p=0.11

30 Chi-square=3.7, df=2, p=0.16

31 Chi-square=0.0, df=2, p=1.00

32 Chi-square=1.1, df=2, p=0.57

33 Chi-square=1.1, df=2, p=0.58

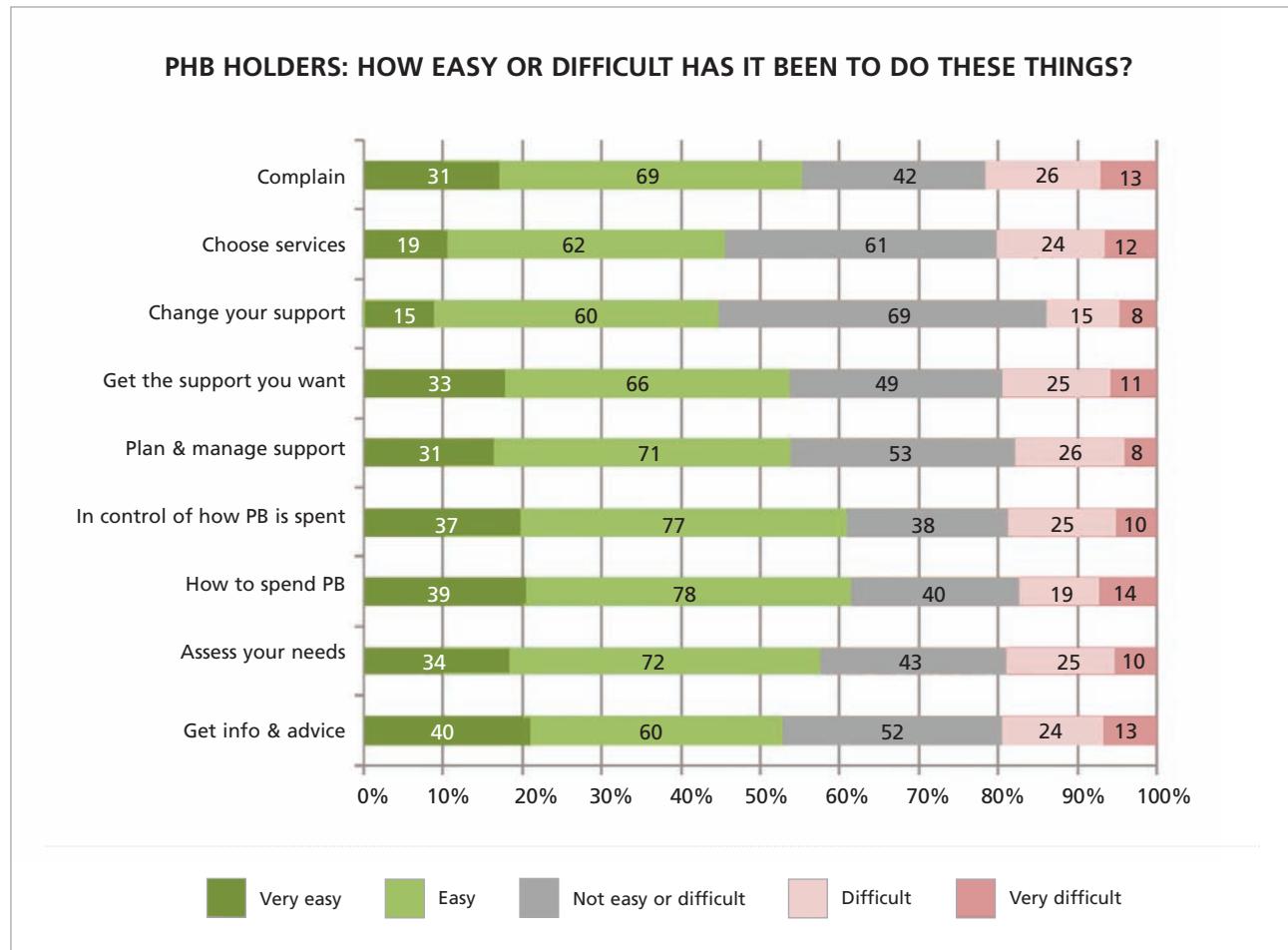
34 Chi-square=0.8, df=2, p=0.69

35 Chi-square=8.5, df=2, p=0.014

36 Chi-square=6.9, df=2, p=0.032

37 Get info/advice chi-square=4.4, df=4, p=0.36; Assess needs chi-square=0.2, df=4, p=1.00; Know how to spend PHB chi-square=3.3, df=4, p=0.50; Be in control of PHB spend chi-square=2.7, df=4, p=0.61; Plan/manage support chi-square=2.2, df=4, p=0.71; Get support chi-square=8.5, df=4, p=0.07; Change support chi-square=6.4, df=4, p=0.17; Choose services chi-square=5.6, df=4, p=0.23; Complain chi-square=2.6, df=4, p=0.62

**Figure 9: NHS or other main support organisations' support for various aspects of the personal health budget process**



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

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The POET survey 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 10 summarises the impact of personal health budgets on the 15 areas of people's lives we asked about. 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. Equivalent statistics from the most recent social care POET survey are reported in the text to give some data for broad comparative purposes.

Overall, over 70% of personal health budget holders reported their budget having a positive impact on their independence (72.6% vs 71.0% social care POET).

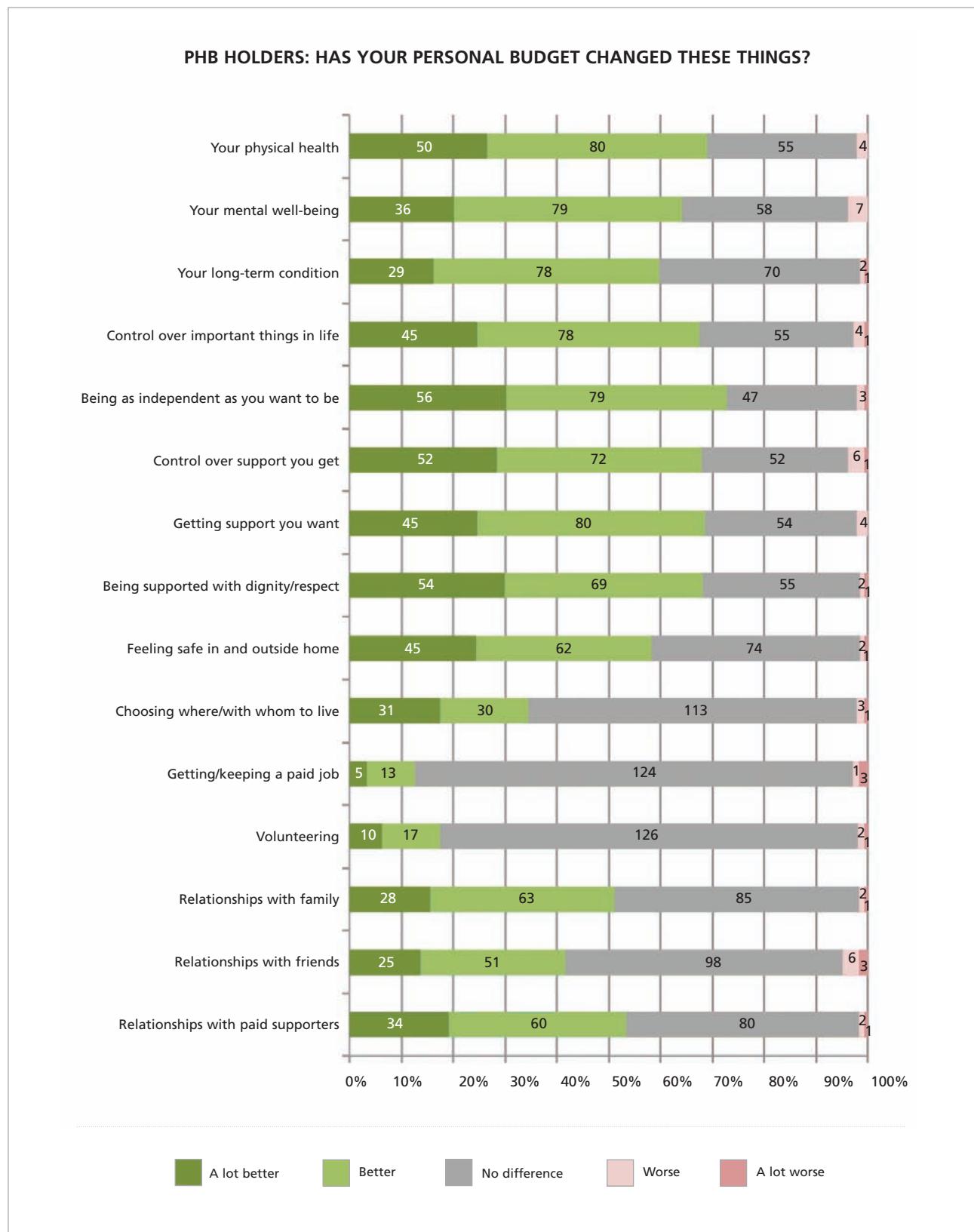
Over 60% of personal health budget holders reported their budget having a positive impact on their physical health (68.8% vs 61.0% social care POET), getting the support they wanted (68.3% vs 71.1% social care POET), being supported with dignity and respect (67.9% vs 75.4% social care POET), being in control of their support (67.7% vs 69.3% social care POET), being in control over the important things in life (67.2% vs 63.4% social care POET), and on their mental wellbeing (63.9% vs 63.6% social care POET).

Over 50% of personal health budget holders reported their budget having a positive impact on the long-term condition for which they held the budget (59.4%, no social care comparative data), feeling safe in and outside the home (58.2% vs 56.2% social care POET), their relationships with people paid to support them (53.1% vs 60.0% social care POET), and their relationships with members of their family (50.8% vs 49.0% social care POET).

Fewer personal health budget holders reported a positive impact of their budget on their relationships with friends (41.6% vs 41.3% social care POET) or choosing where and with whom they lived (34.3% vs 36.2% social care POET). Very few people reported a positive impact on volunteering (17.3% vs 19.2% social care POET) or getting and keeping a paid job (12.3% vs 11.6% social care POET). In all these areas of life most people reported their personal health budget making no difference.

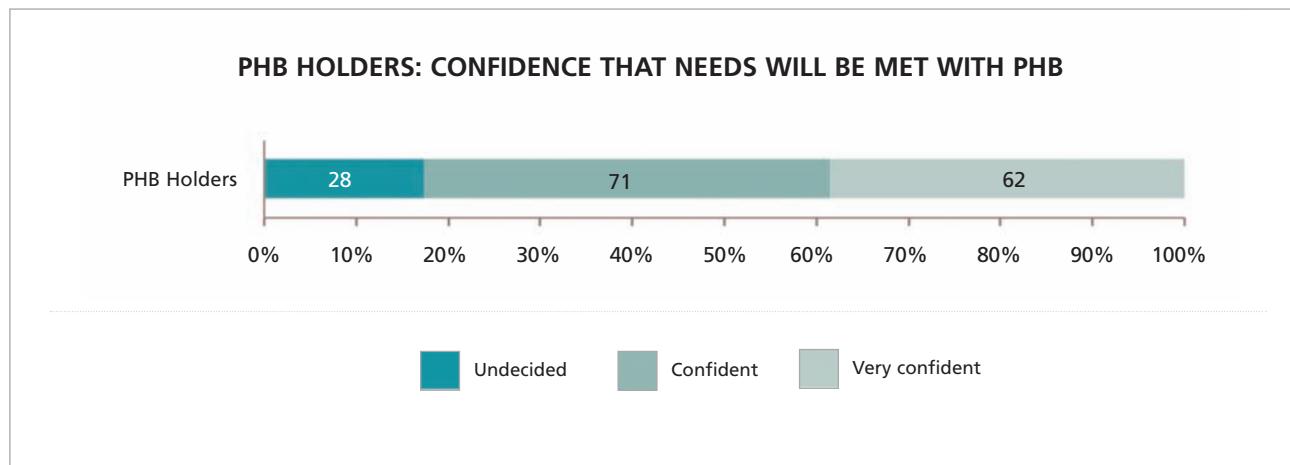
Overall, as with the social care POET, small numbers of people (between 1.7% and 4.9%) reported their personal health budget having a negative impact on any of these 15 aspects of people's lives.

Figure 10: Outcomes of personal health budgets



Finally, we asked personal health budget holders how confident they were that their needs would be met with their personal health budget. Figure 11 below shows that a big majority of personal health budget holders (82.6%) felt confident or very confident that their needs would be met, with the remainder (17.4%) undecided; no-one reported feeling unconfident or very unconfident that their needs would be met.

**Figure 11: Personal health budget holders' confidence that their needs will be met with their personal health budget**



## Experience of the impact of personal health budgets

Respondents were asked if they wished to make any further comment about having a personal health budget. A total of 120 people made comments. The length of response varied from a couple of words to several paragraphs, with most people providing just a few sentences. Responses tended to illustrate peoples experience of the process of taking control of a personal health budget or the impact the personal budget had on their life. The overwhelming majority of responses were either positive or negative, though a few were mixed. This meant it was possible in nearly all cases to identify responses as either 'broadly positive' or 'broadly negative'.

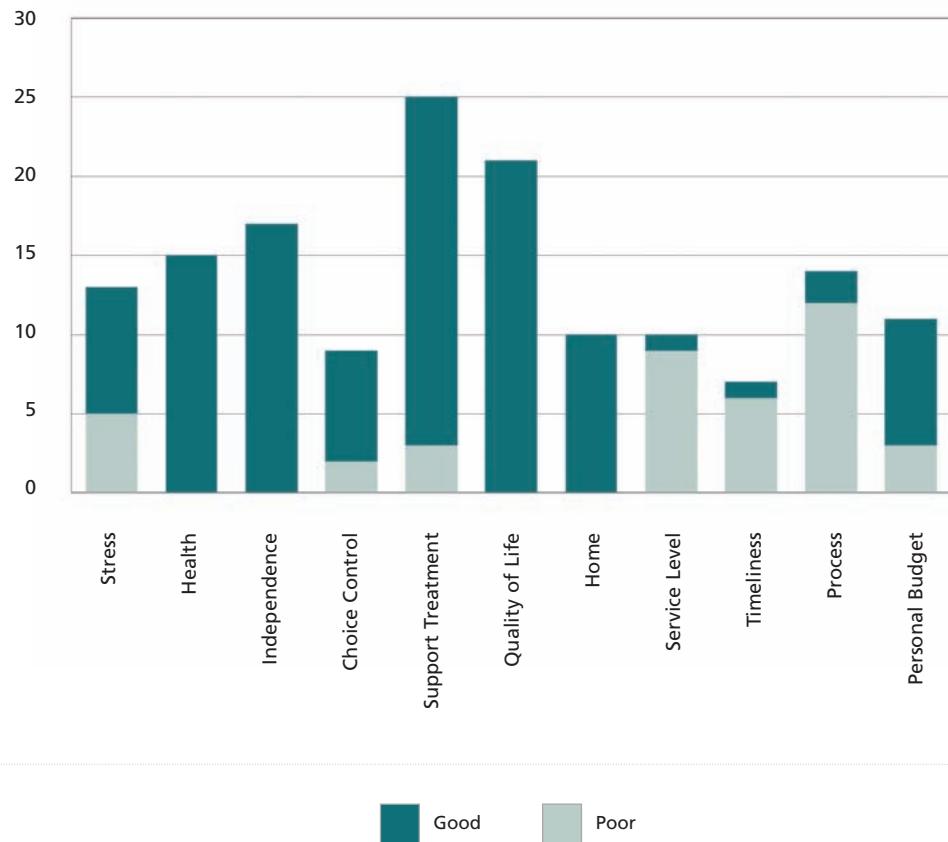
In addition to their experience of personal health budgets people's comments covered a wide range of matters of concern to them, in particular people described their own personal circumstances, and the reason why they had a personal health budget.

Several specific themes were evident in the responses people provided, the responses were categorised by these themes. The themes were not mutually exclusive and many comments covered a number of themes, so comments were not necessarily assigned exclusively to just one category exclusively. The following categories were felt to offer a useful way to describe and quantify the themes emerging from the various responses. Some of the themes were similar to those identified in previous surveys of recipients of social care budget recipients.

<b>Stress</b>	People spoke about the emotional pressure or worry and stresses that were caused or relieved by the personal budget. Many people spoke about stress and worry being alleviated by the support provided through a personal budget, where people talked about additional stress this was commonly around the responsibility of managing the budget.
<b>Health</b>	Many people commented on the impact that the personal health budget had on their health, this was always in positive terms. People commented on how the budget had helped them towards recovery or to reduce the impact of their condition on their life. People spoke about both physical and mental health improving.
<b>Independence</b>	People commented on the personal budget and how it had improved their independence. This was often in terms of improved mobility, access to local community facilities and services. People also wrote about having their needs met in their own home rather than in hospital or a care home.
<b>Choice Control</b>	People commented on the increased choice and control personal health budgets had given them over their treatment and support and in other aspects of life. Where comments were negative this was related to a failure to exercise increased choice that had initially been anticipated.
<b>Support Treatment</b>	People wrote mostly in positive terms about the choices personal budgets offered in relation to their treatment and or support. People valued increased flexibility and support that was tailored to the person's individual needs and circumstances. People also increased control over where and when treatment and support was offered.

Quality of life	People commented on a wide range of improvements to their quality of life associated with the personal health budget, including improved physical and emotional wellbeing, and improved ability to manage their health condition. People also commented on improved relationships with their family. Some people reported that the quality of life of their family and friends had also improved.
Home	People wrote positively about the impact their personal budget had on their home life. People spoke about the budget helping them remain at home, receive treatment at home or making environmental improvements to their home.
Service Level	When people wrote about the amount of budget or service available they did so almost without exception in negative terms. Though sometimes people wanted more of a good thing. Some negative comments were concerns that a pilot and so the budget would come to an end.
Timeliness	People reported delays in the personal budget process as some difficulties were experienced around assessment, support planning, arranging support or treatment and making payments. Some people who commented negatively about this part of the process went on to indicate that things had improved over time once the plan had been implemented.
Process	Where people commented on their experience of the process of taking control of a budget this was almost always in negative terms. People commented on difficulty agreeing the level of the budget, spending or accounting for the budget, a lack of information advice and support.
Personal Health Budget	People commented about the idea of personal health budget. More often in positive than negative. Often people distinguished their experience of the personal health budgets from the idea of having control of a budget.

### PERSONAL HEALTH BUDGET RECIPIENT'S COMMENTS ON THEIR EXPERIENCE



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

Figure 10 above 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?

To address these questions, we checked whether there were associations between all the factors mentioned above and better outcomes on all the outcome indicators. Because personal health budget holders' confidence in their personal budgets to meet their needs was almost uniformly positive, we could not conduct similar analyses concerning confidence.

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 following.

The following tables report the odds ratios for each factor against each outcome indicator. Because of the large amount of information contained in these tables, colour coding has been used to help interpretation of the tables, as follows:

- Cells are shaded light green if the odds ratio shows a statistically significant positive relationship between the factor and the outcome indicator (in other words, having the factor is associated with an increased chance of a positive impact being reported), and if the odds ratio is less than 3.
- Cells are shaded dark green if the odds ratio is 3 or greater (i.e. if the factor is present, people are at least three times more likely to report their personal health budget having a positive impact).

- Cells are shaded light pink if the odds ratio shows a statistically significant negative relationship between the factor and the outcome indicator (in other words, having the factor is associated with a reduced chance of a positive impact being reported), and if the odds ratio is greater than 0.33.
- Cells are shaded dark pink if the odds ratio is 0.33 or less (i.e. if the factor is present, people are at least three times less likely to report their personal health budget having a positive impact).

Because the statistical significance of odds ratios is partly dependent on the number of respondents in specific categories, we have also used the following shading where odds ratios are relatively large but do not reach statistical significance:

- Cells are shaded with light gray if the odds ratio is between 2 and 3.
- Cells are shaded with dark gray if the odds ratio is 3 or greater.
- Cells are shaded with light yellow if the odds ratio is between 0.33 and 0.5.
- Cells are shaded with dark yellow if the odds ratio is 0.33 or less.

We do not report these as significant associations in the text, but they are presented in the tables for the reader to consider as tentative possible associations.

Table 1 shows whether three personal factors (the personal health budget holder being less than 65 years old, female, or reporting themselves as in very good/good health), the organisation funding the personal health budget (PCT, NHS or council), 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 the 15 areas of people's lives we asked about.

Table 1 shows firstly that people's age, gender or self-reported health status were largely unrelated to any of the outcome indicators, indicating that personal health budgets were not working particularly well (or not) for particular groups.

Table 1 also shows that people having a PCT as their personal health budget funder were more likely to report a positive impact of their personal health budget on their physical health (three times more likely) and the long-term health condition for which they were holding a budget (twice as likely). Having an NHS Trust as the personal health budget was not associated with any of the 15 outcome indicators. People having a council-funded personal health budget were less likely to report positive outcomes on their physical health (three times less likely) or the long-term for which they were holding a personal budget (three times less likely).

People who had been receiving social services support before their personal health budget were no more or less likely to report a positive impact of their personal health budget than people who had not been receiving such support before their budget.

**Table 1: 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 outcome: Personal factors and the main PHB organisation						
	Less than 65 years old	Female gender	Very good/good health	PCT organising PHB	NHS Trust organising PHB	Council organising PHB	Council support before PHB
Physical health	1.69	1.38	1.08	3.07	0.54	0.33	0.74
Mental wellbeing	0.85	0.89	1.96	1.60	0.69	0.72	1.04
Long-term condition	2.03	1.08	1.30	2.02	0.77	0.38	0.88
Control over life	1.20	0.77	1.13	1.65	0.67	0.73	1.23
Independence	1.59	1.29	1.56	1.70	0.76	0.56	1.39
Control over support	1.06	1.06	1.22	1.50	0.99	0.48	0.95
Getting support you want	1.16	0.94	1.38	1.54	0.68	0.81	1.49
Supported with dignity	1.19	1.03	1.62	1.58	0.54	1.15	1.68
Feeling safe	0.99	1.07	0.81	1.24	0.92	0.76	1.01
Choosing where to live	1.38	0.80	0.72	1.03	1.19	0.72	1.33
Getting/keeping paid job	1.54	0.45	2.19	1.48	0.79	0.66	1.57
Volunteering	0.52	0.79	1.56	1.56	1.13	0.20	1.14
Relationships with family	1.10	1.00	1.49	1.68	0.67	0.69	1.03
Relationships with friends	0.83	0.76	1.83	1.10	0.72	1.39	1.07
Relationships with paid supporters	0.94	0.94	1.22	0.89	0.71	2.22	1.77

Table 2 below 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 the 15 outcome indicators we asked about.

Table 2 shows firstly that if people had held their personal health budget for more than one year they were more likely to report a positive impact of their budget on being supported with dignity (almost twice as likely) and their relationships with people paid to support them (more than twice as likely).

In terms of the type of personal budget that people held, there were different patterns of associations with outcomes for different types of budget:

- People with a direct payment paid directly to them were more than twice as likely to report a positive impact of their budget on them getting the support they want when they want it.
- Personal health budgets in the form of a direct payment paid to a broker were not associated with any outcome indicator.
- People with a direct payment looked after by family or friend were almost four times less likely to report a positive impact of their budget on the long-term condition for which they held the budget, but were much more likely (at least four times more likely) to report positive impacts on their relationships with family, friends, and people paid to support them.
- People with a personal health budget managed by their provider were five times more likely to report a positive impact on the long-term condition for which they held a budget, and over three times more likely to report a positive impact on the control they had over the important things in life.
- Personal health budgets managed by the NHS or council were not associated with any outcome indicator.

People who knew the cost of their support were almost eight times more likely to report a positive impact of their budget on their volunteering activity, and more than twice as likely to report positive impacts on their physical health, the control they have over their support, feeling safe in and outside the home, and their relationships with their family.

**Table 2: 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/friend	Provider-managed PHB	NHS/council-managed PHB	Know support costs
Physical health	0.75	0.87	1.19	0.97	2.21	2.08	2.36
Mental wellbeing	1.11	1.29	1.34	1.15	1.47	0.86	1.42
Long-term condition	0.60	0.95	1.38	0.27	5.05	2.04	2.00

Control over life	1.12	1.38	0.61	2.40	3.47	1.30	1.62
Independence	1.14	1.63	0.64	1.81	1.33	0.83	1.42
Control over support	1.20	1.81	0.77	2.34	1.02	0.88	2.38
Getting support you want	1.72	2.40	1.01	1.27	0.99	1.05	2.00
Supported with dignity	1.93	1.52	0.65	2.31	1.30	1.33	1.55
Feeling safe	1.14	1.55	0.62	3.69	1.04	1.43	2.89
Choosing where to live	1.48	1.46	0.68	2.12	1.21	0.56	2.43
Getting/keeping paid job	1.02	0.95	1.10	0.87	2.53	1.22	2.34
Volunteering	0.87	0.64	2.31	0.61	1.43	1.07	7.87
Relationships with family	1.31	0.90	1.18	4.83	1.46	0.43	2.33
Relationships with friends	1.34	1.04	1.02	4.13	0.85	0.58	1.46
Relationships with paid supporters	2.30	1.43	1.04	6.33	0.63	0.50	1.56

Table 3 shows potential associations between various aspects of the personal health budget planning process (who helps the person to plan, and whether the personal health budget feels their views are incorporated in their support plan) and positive outcomes for the 15 outcome indicators we asked about.

In terms of sources of help for planning, there were different patterns of associations with outcomes according to the source of planning support (please also note that these sources of support are not mutually exclusive could record getting help to plan from more than one source):

- People who had help to plan from family/friends were almost four times more likely to report a positive impact of their budget on their relationships with people paid to support them, and more than twice as likely to report positive impacts on the control people had over their support, getting the support they wanted when they wanted it, feeling safe in and outside the home, choosing where to live and whom to live with, and their relationships with family and friends.
- Getting help to plan from someone in the council was not associated with any outcome indicator to a statistically significant level.

- People who planned their support themselves without any help were 13 times more likely to report a positive impact of their budget on their capacity to get and keep a paid job, and three times more likely to report a positive impact on the long-term condition for which they were getting a personal health budget.
- People who got help to plan from someone in the NHS were almost three times less likely to report a positive impact of their budget on their capacity to get and keep a paid job.
- People who got help from someone independent of the council or NHS were almost three times more likely to report a positive impact of their budget on their volunteering activities.

Finally, Table 3 shows that people who felt that their views were incorporated into their support plan were 10 times more likely to report a positive impact of their budget on them getting the support they wanted when they wanted it, and four times more likely to report a positive impact on their physical health.

**Table 3: 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	Someone else helps to plan	Views included in plan
Physical health	0.94	0.69	1.33	1.09	1.02	4.31
Mental wellbeing	1.02	0.89	1.94	0.87	0.88	2.34
Long-term condition	0.76	0.58	3.48	0.97	1.31	2.81
Control over life	1.64	0.85	1.44	0.61	0.88	2.67
Independence	1.82	1.30	1.81	1.13	0.66	2.40
Control over support	2.89	2.08	1.40	1.06	0.99	3.38
Getting support you want	2.40	1.31	2.42	0.82	0.79	10.10
Supported with dignity	1.57	2.06	1.70	1.24	0.80	1.43
Feeling safe	2.28	2.02	1.41	1.00	1.16	3.50
Choosing where to live	2.16	0.76	1.27	0.91	1.54	1.43

Getting/keeping paid job	0.25	n/c	13.16	0.34	1.51	1.01
Volunteering	0.36	1.07	1.32	0.99	2.86	1.68
Relationships with family	2.99	1.06	1.30	0.78	0.90	1.31
Relationships with friends	2.14	1.97	1.20	0.89	0.87	2.02
Relationships with paid supporters	3.82	2.07	1.07	1.01	0.98	4.26

n/c=Odds ratio not calculable

Table 4 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 the 15 outcome indicators we asked about.

As Table 4 shows, making almost all aspects of the personal health budget process easier was associated with positive outcomes for a majority of indicators:

- Making it easy to get information and advice, to know how to spend the personal health budget, to have control over how the personal budget is spent, to plan and manage support, and to change the person's support, were all associated with positive impacts in at least 10 of the 15 outcome indicators we asked about.
- Making it easy for the person's needs to be assessed and for the person to get the support they wanted when they wanted it were associated with positive impacts in eight and nine outcome indicators respectively.
- Making easy aspects of the personal process that fewer people had possibly experienced, such as changing the person's support or complaining, were associated with positive impacts on fewer outcome indicators (six and five respectively).
- Relatively few of these personal health budget factors (three or fewer) were associated with better outcomes for: getting and keeping a paid job, volunteering, or choosing where to live/whom to live with. Getting good information and advice and knowing how the personal health budget could be spent were important factors for these outcomes.
- Four of these personal health budget factors were associated with better outcomes for: being as independent as the person wants to be, being supported with dignity and respect, or relationships with paid supporters. Knowing and controlling the personal health budget spending, and being able to plan, manage, choose and change support seemed particularly important for these outcomes.

**Table 4: Experience of the personal health budget process: Associations with positive outcomes for personal health budget holders**

OUTCOME	Factors potentially associated with outcome: How easy has the PCT/NHS Trust/council funding your PHB made it to...								
	Get info and advice	Assess your needs	How to spend PHB	Control on how PHB is spent	Plan and manage support	Get support you want	Change your support	Choose services	Complain
Physical health	2.52	3.14	2.00	3.30	3.04	1.59	1.77	1.83	1.72
Mental wellbeing	3.69	3.54	2.00	2.58	2.17	1.38	1.74	2.09	1.44
Long-term condition	2.74	1.86	2.56	2.93	2.41	1.90	1.75	3.44	2.21
Control over life	2.52	1.55	2.64	3.58	2.66	2.69	1.74	2.77	1.85
Independence	1.86	1.67	1.90	3.00	2.63	2.46	1.69	2.25	1.53
Control over support	2.57	2.32	2.77	6.96	3.72	2.79	1.52	3.33	1.50
Getting support you want	2.79	2.85	2.43	3.58	2.93	3.74	2.60	4.21	2.53
Supported with dignity	1.79	1.91	2.65	1.86	1.82	2.19	3.03	2.38	1.39
Feeling safe	1.53	2.27	2.60	3.21	2.48	2.11	2.70	2.49	2.01
Choosing where to live	2.18	1.78	2.71	2.29	1.40	1.04	1.91	1.64	1.40
Getting/keeping paid job	4.59	3.31	4.92	1.26	1.60	1.65	1.29	2.62	0.96
Volunteering	1.24	0.86	2.27	1.55	1.22	0.73	1.44	1.01	0.73
Relationships with family	2.25	2.12	3.29	3.83	2.54	2.01	2.75	2.86	2.26
Relationships with friends	3.15	2.70	6.00	4.55	2.79	3.25	4.50	3.85	3.75
Relationships with paid supporters	1.56	1.32	1.86	2.76	2.17	1.72	3.13	2.34	1.69

# Findings – Carers

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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 or don't make to carers' lives
- What factors are associated with better outcomes for carers.

## Who responded to the POET survey?

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As mentioned earlier, a total of 117 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, the totals reported throughout the report are unlikely to add up to this overall total.

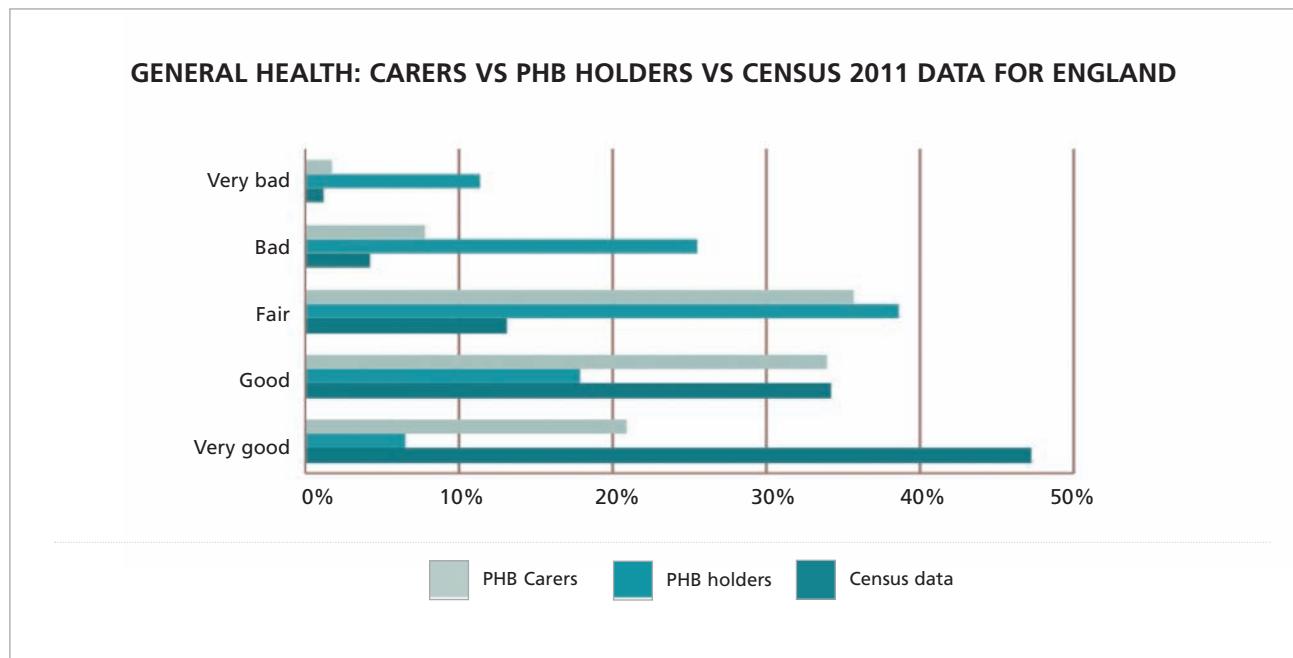
Equalities monitoring information for carers is presented in detail in Appendix 2. In outline, this information shows:

- Most respondents (70.2%) were women.
- In terms of age, 12.9% of carers were aged 16-44 years, 53.4% were aged 45-64 years, and 33.6% were aged 65 years or over.
- Most respondents were white (91.5%), with 2.6% of respondents not giving this information.
- Most respondents were Christian (62.4%), with 9.4% of respondents not giving this information and 23.9% reporting themselves to have no religion.
- Most respondents reported themselves to be heterosexual/straight (83.8%), with the other 16.2% of respondents not giving this information.
- Just over a quarter of carers (27.7%) reported themselves to have a disability, most commonly a physical disability (12.0%) and/or a longstanding illness/health problem (11.1%).

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 the last 12 months 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. Over half of carers (54.8%) reported their health as good or very good, compared to less than a quarter (24.4%) of

personal health budget holders and over three-quarters (79.4%) of the general population. Almost 10% of carers (9.5%) reported their health as bad or very bad, compared to over a third (36.9%) of personal health budget holders and less than 10% (6.4%) 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)**

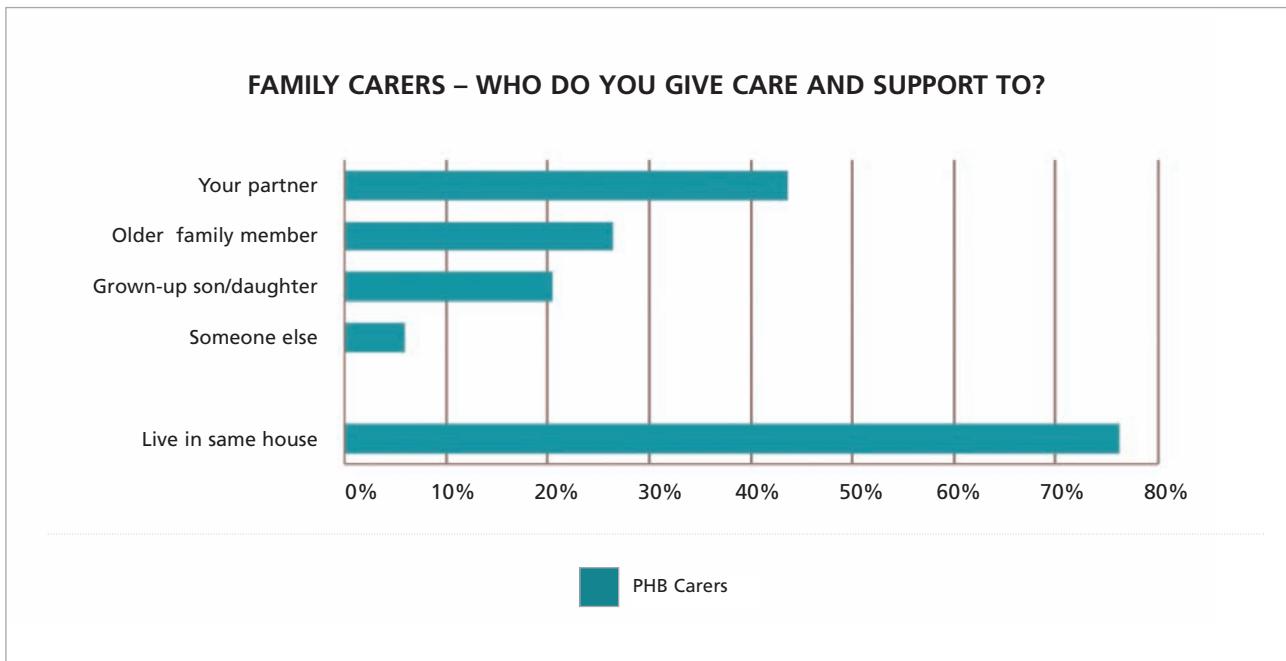


## What are the circumstances of carers?

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 (43.6%), followed by an older family member (usually a parent; 26.5%) then a grown-up son or daughter (20.5%), with a small proportion of carers supporting someone else (e.g. a friend or neighbour; 6.0%). Figure 13 also shows that over three quarters of carers (76.3%) 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 half of carers were caring for more than 50 hours per week.

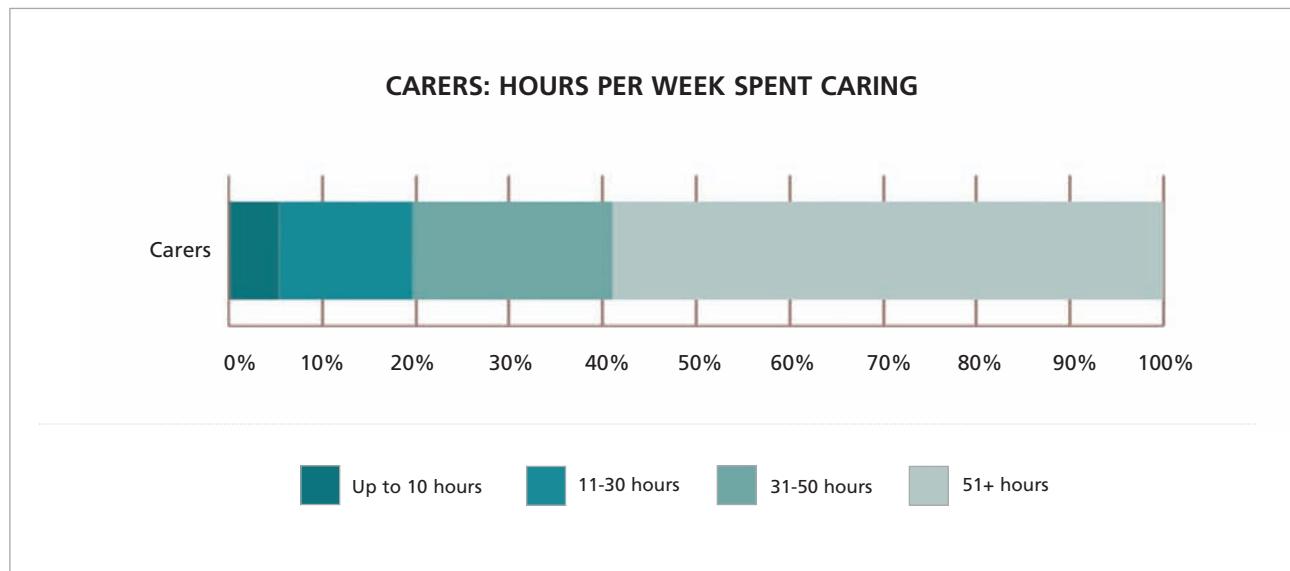
Carers who were living in the same house as the person they were caring for<sup>38</sup> and carers who were caring for their partner/spouse<sup>39</sup> on average reported spending more hours caring. Carers who were caring for an older family member<sup>40</sup> on average reported spending fewer hours caring.

38 Mann-Whitney  $U=373.5$ ,  $n=112$ ,  $p<0.001$

39 Mann-Whitney  $U=866.5$ ,  $n=112$ ,  $p=0.004$

40 Mann-Whitney  $U=866.5$ ,  $n=112$ ,  $p=0.004$

**Figure 14: Estimated hours per week spent caring**



## Carers and personal health budgets

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 support from the local authority before getting a personal health budget, whether the carer knew the amount of the personal health budget held by the person they were supporting, and whether carers were getting personal budget support themselves.

Details of these findings are presented in Appendix 3. In outline, this information shows:

- Of the personal health budget holders being supported by carers, 45.5% had had their personal budget for less than a year, 45.5% had had their personal budget between one and three years, and 8.9% had had their personal budget for over three years.
- Over half (60.0%) of the people being supported by carers had received social care support before their personal health budget.
- Over three quarters of carers (79.8%) knew the amount of the personal health budget held by the person they were supporting.
- Less than a quarter of carers (22.2%) reported that they were receiving a carers' personal budget, and very few carers (2.8%) reported that they were receiving their own personal budget for their own needs.

## Carers' experience of the personal health budget process

In addition to the analysis of the information that carers wrote, we also asked carers two questions about their experience as carers of the personal health budget process for the person they were supporting; whether carers felt their views were included in the support plan for the person they were caring for, and their overall experience as carers of how easy or hard they had found the personal health budget process.

Figure 15 below shows that a vast majority of carers (86.5%) felt that their views were fully included in the support plan of the person they were caring for.

**Figure 15: Were carers' views fully included in the personal health budget holder's support plan?**

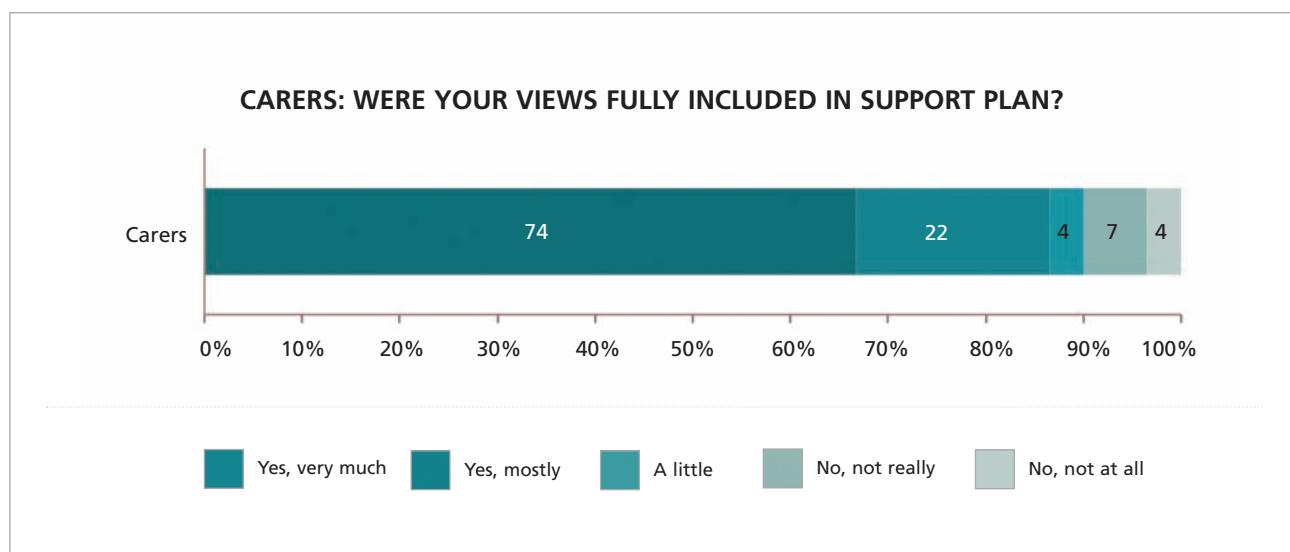
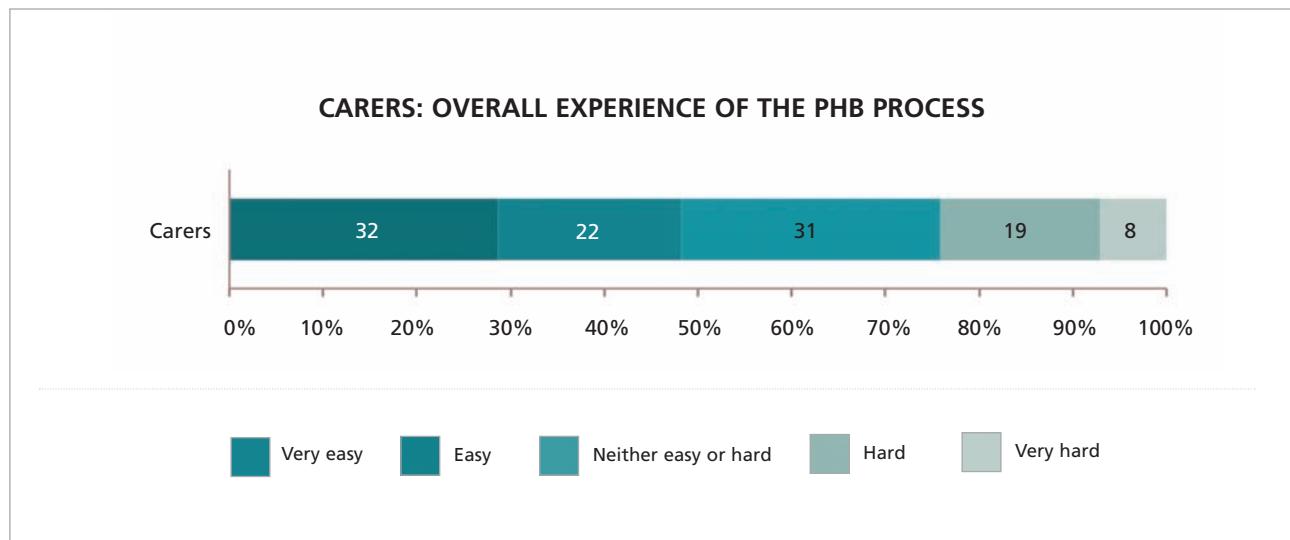


Figure 16 shows that almost half of carers (48.2%) felt that the personal health budget process was very easy or easy, but almost a quarter of carers (24.1%) felt that the personal health budget process was hard or very hard.

**Figure 16: Carers' overall experience of the personal health budget process**



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

The POET survey asks carers whether personal health budgets for the person they are supporting have made a difference to 10 aspects of the carers' lives, and if so whether this difference has been positive or negative. Figure 17 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. Equivalent statistics from the most recent social care POET survey are reported in the text to give some data for broad comparative purposes.

Over 60% of carers reported a positive impact of personal health budgets held by the person they care for on three aspects of their own lives as carers: their quality of life (70.2% vs 60.4% social care POET), support for them to continue caring (67.6% vs 69.3% social care POET) and their finances (60.2% vs 52.2% social care POET).

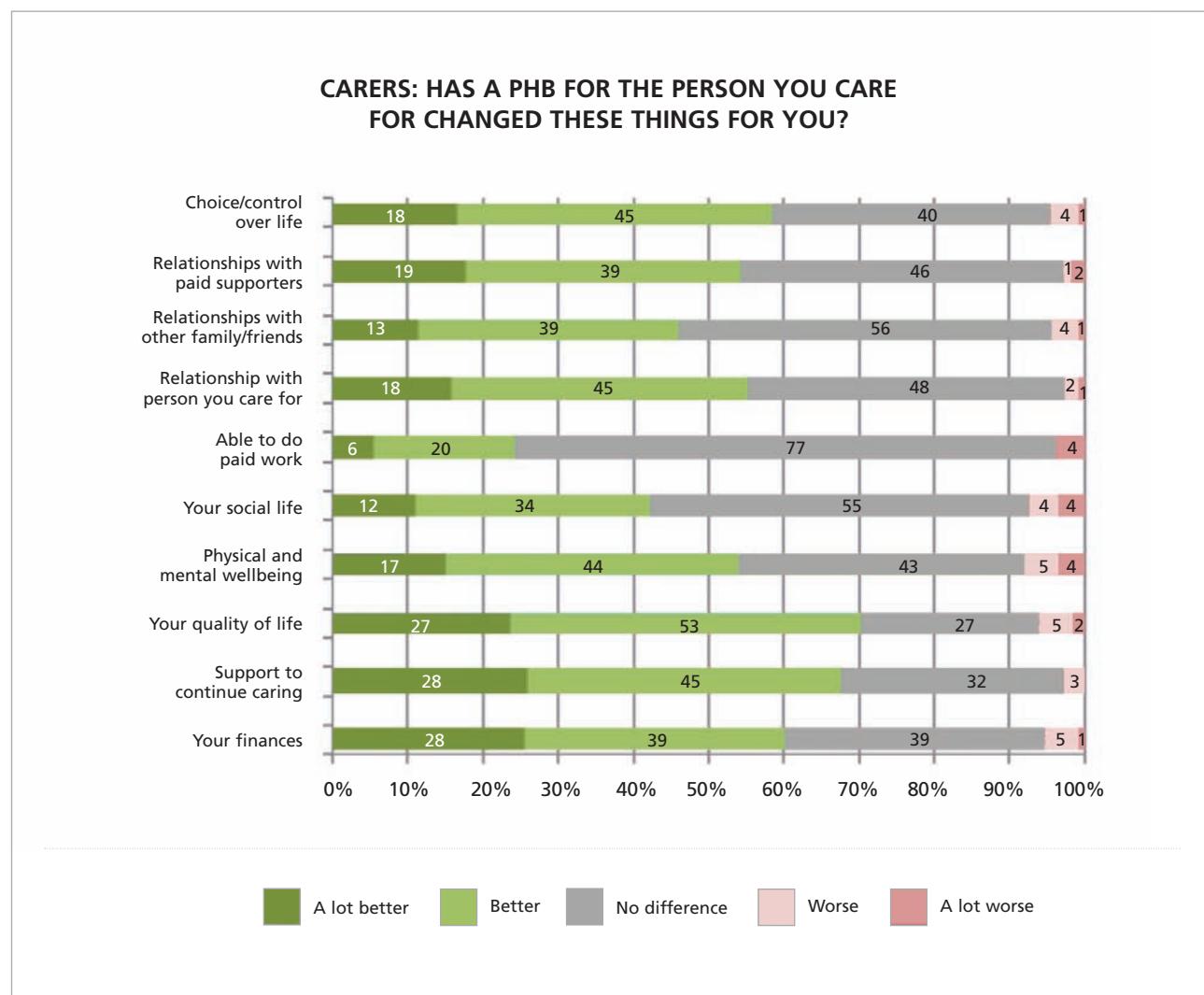
Between 50% and 60% of carers reported a positive impact of personal health budgets held by the person they care for on three further aspects of their own lives as carers: their choice and control over their own lives (58.4% vs 43.8% social care POET), their relationships with people paid to support the budget holder (54.2%, no social care comparative data) and their physical and mental wellbeing (53.9% vs 52.9% social care POET).

For another three outcome domains for carers, carers were relatively evenly split on whether personal health budgets held by the person they care for had had a positive impact or made no differences in the areas of the carer's social life (42.2% improved, 50.5% no difference; 41.2% improved in social care POET), and the carer's relationships with the person cared for (47.5% improved, 42.1% no difference; 46.9% improved in social care POET) and other family/friends (46.0% improved, 49.6% no difference; 41.2% improved in social care POET).

Most carers (72.0% vs 69.2% social care POET) reported that personal health budgets held by the person they care for had made no impact on their own capacity to get and keep a paid job.

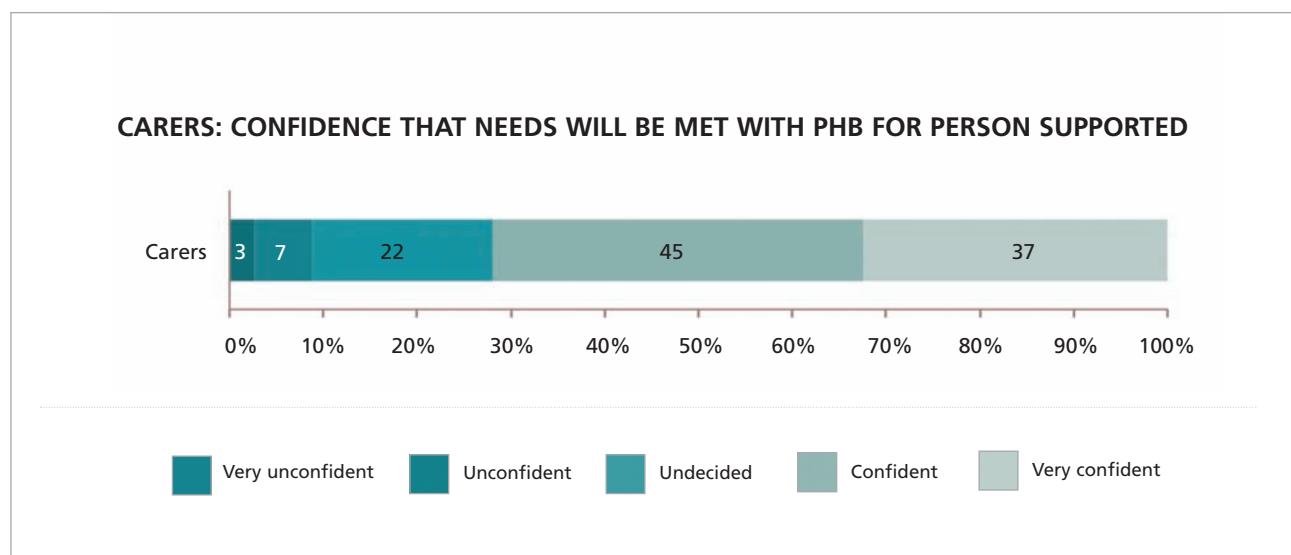
As with the social care POET survey, less than 10% of carers reported any areas of their lives getting worse as a result of personal health budgets.

**Figure 17: Outcomes for carers**



Finally, we asked carers how confident they were that their needs would be met with the personal health budget for the person they were supporting. Figure 18 below shows that almost three quarters of carers (72.0%) felt confident or very confident that their needs would be met, and a small minority (8.7%) were unconfident or very unconfident.

**Figure 18: Carers' confidence that their needs will be met with the personal health budget for the person they are supporting**



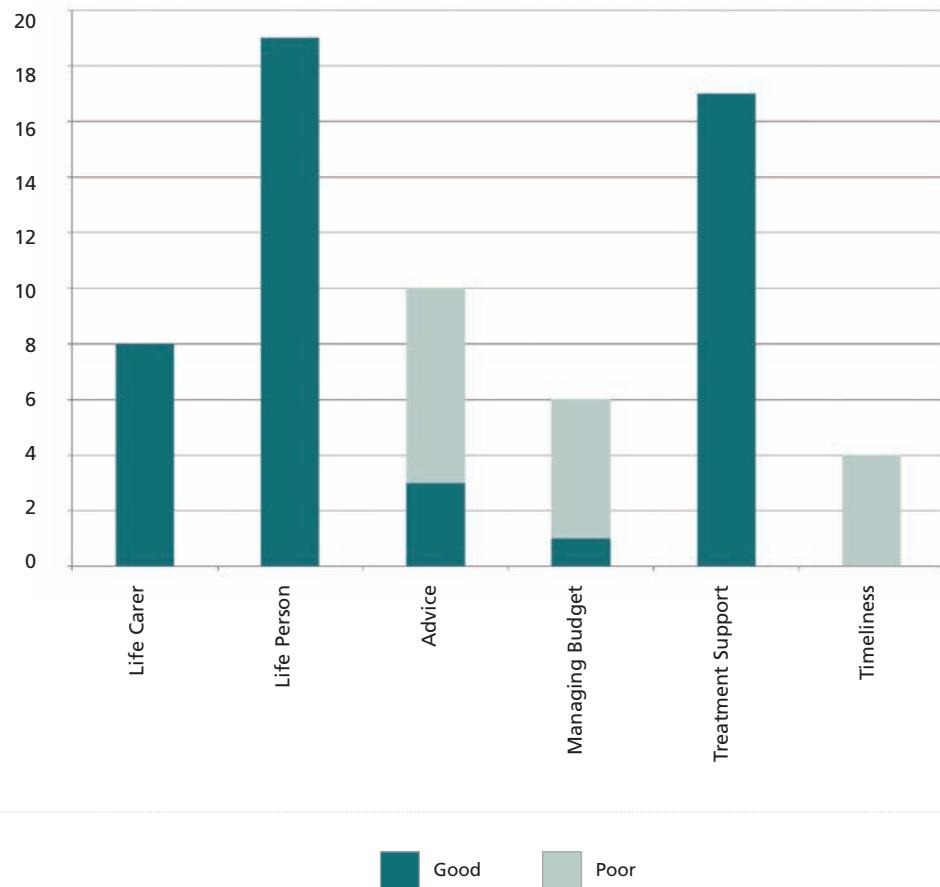
## Carer's experience of the impact of personal budgets on them

As with personal budget holders, carers were asked if they wished to make any further comment about having a personal health budget. In total, 41 people made comments. As with personal budget holders, the length of response made by carers varied from a couple of words to several paragraphs, with most people providing just a few sentences.

Several specific themes were evident in the responses people provided, the responses were categorised by these themes and labeled as either broadly positive or broadly negative. Themes were not mutually exclusive and many comments covered at least two of the themes, so comments were not necessarily assigned exclusively to just one category. The following categories were felt to offer a useful way to describe and quantify the themes emerging from the various responses. Some of the themes were similar to those identified in previous surveys of recipients of social care budget recipients.

<b>Life Carer</b>	Carers spoke about the impact of the personal health budget for the person they care for on their own life. This was always in positive terms. People described how having care and support available to the person they cared for had improved their life as a carer.
<b>Life Person</b>	Without exception people spoke in positive terms about the impact of personal budgets on the life of the person they cared for. People commented on the impact that improved treatment and support arrangements had on the quality of life of the person they cared for.
<b>Advice</b>	When people commented on the guidance, advice and support available they did so in both negative terms and positive terms. People wrote about a lack of clear guidance info and advice, some people reported a lack of support. Others commented how important good personal advice from professionals had been to them.
<b>Managing Budget</b>	When people wrote about the experience of managing a personal budget they did so almost invariably in negative terms. People commented about the additional work that controlling a budget placed on them as carers.
<b>Treatment Support</b>	People wrote entirely positively about support and treatment choices. People commented on the value of having personalised support and treatment available to the person they cared for.
<b>Timeliness</b>	Difficulties were experienced by some people as they found that the process took too long and there were delays in getting the personal health budget up and running.

## CARERS OF PERSONAL HEALTH BUDGET RECIPIENT'S COMMENTS ON THEIR EXPERIENCE



## What factors are associated with positive outcomes for carers?

Figure 15 shows that personal budgets held by the people they care for are perceived by carers to have a broadly positive or neutral impact on their own lives as carers. In this section of the report we will ask three further questions:

- 1) Are there inequalities in carer outcomes of personal health budgets for the person they are supporting, depending on carers' age, gender, or self-reported health?
- 2) Are aspects of carer circumstances (whether the carer lives in the same house as the person they are supporting, weekly hours of caring, who the carer is caring for) associated with outcomes for carers?
- 3) Are aspects of personal health budget usage for the person being supported (length of time with personal budget, previous local authority support, personal budget support for carers themselves), and carer experiences of the personal health budget process (the carer knows the amount of the personal health budget holder's budget, inclusion of carer views in the person's support plan, overall carer rating of the personal health budget process) associated with the outcomes for carers?

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

The analyses we conducted for carers and the format in which we present the results are the same as we used to investigate associations with outcomes for personal health budget holders (see above).

Tables 5 and 6 report the odds ratios for each factor against each outcome indicator for carers.

Because of the large amount of information contained in these tables, colour coding has been used to help interpretation of the tables, as follows:

- Cells are shaded light green if the odds ratio shows a statistically significant positive relationship between the factor and the outcome indicator and if the odds ratio is less than 3.
- Cells are shaded dark green if the odds ratio is 3 or greater.
- Cells are shaded light pink if the odds ratio shows a statistically significant negative relationship between the factor and the outcome indicator and if the odds ratio is greater than 0.33.
- Cells are shaded dark pink if the odds ratio is 0.33 or less.

Because the statistical significance of odds ratios is partly dependent on the number of respondents in specific categories, we have also used the following shading where odds ratios are relatively large but do not reach statistical significance:

- Cells are shaded with light gray if the odds ratio is between 2 and 3.
- Cells are shaded with dark gray if the odds ratio is 3 or greater.
- Cells are shaded with light yellow if the odds ratio is between 0.33 and 0.5.
- Cells are shaded with dark yellow if the odds ratio is 0.33 or less.

We do not report these as significant associations in the text, but they are presented in the tables for the reader to consider as tentative possible associations.

Table 5 below firstly shows that there were no significant differences in the proportion of carers reporting positive outcomes on any of the outcome indicators according to their age, gender, or self-reported health.

Table 5 also shows that carers living in the same house as the person they were supporting were around three times more likely to report positive impacts of the person's personal health budget on carers' finances, capacity to continue caring and quality of life. Other aspects of carers' circumstances (estimated weekly hours spent caring, whether the carer was caring for a partner, older family member or grown-up son/daughter) were not associated with any outcome indicators for carers.

**Table 5: Personal factors and aspects of carers' circumstances: Associations with positive outcomes for carers**

OUTCOME FOR CARER	Factors potentially associated with outcome: Personal factors and carers' circumstances							
	Carer less than 65 years old	Carer female gender	Carer very good/good health	Carer living in same house	Carer caring for 50+ hours per week	Carer caring for partner	Carer caring for older person	Carer caring for grown-up son/daughter
Finances	1.52	0.68	1.08	3.40	0.97	1.55	0.74	1.20
Support to continue caring	1.06	0.89	1.28	2.64	1.26	0.93	0.77	2.18
Quality of life	0.61	1.06	1.57	2.83	1.02	1.58	0.85	1.36
Physical and mental wellbeing	0.92	1.22	1.15	1.89	1.02	1.65	0.97	1.14
Social life	0.84	0.96	2.00	2.05	0.85	1.30	0.61	1.21
Getting/keeping paid job	0.54	1.70	1.20	0.75	0.51	0.44	1.62	1.39
Relationship with person cared for	0.78	0.72	0.72	1.26	0.93	1.12	0.90	1.07
Relationships with other family/friends	0.73	1.29	1.34	0.77	0.95	0.51	1.24	1.88
Relationships with paid supporters	1.09	0.83	1.25	0.89	1.24	0.69	0.87	1.95
Choice and control over life	0.71	2.16	1.09	1.59	0.93	1.10	0.69	2.01

In terms of the personal health budget held by the person being supported, the length of time the budget had been held was not associated with any outcomes for carers. If the personal health budget holder had been receiving local authority support prior to their budget, carers were over three times more likely to report the personal health budget having a positive impact on carers' relationships with those paid to support the budget holder.

Carers with a separate carers' budget were no more or less likely to report positive outcomes on any indicator than carers without a separate budget.

Carers who knew the amount of the personal health budget held by the person they were supporting were much more likely to report positive impacts of the budget on a wide range of outcomes:

- These carers were more than six times more likely to report a positive impact of the budget on their capacity to care.
- These carers were more than four times more likely to report positive impacts on their finances, their quality of life and their physical and mental wellbeing.
- These carers were more than three times more likely to report positive impacts on their relationships with those paid to support the budget holder, and on carers' choice and control over their own lives.
- These carers were more than twice as likely to report a positive impact on their relationship with the person they were supporting.

Associations with carer outcomes were even stronger according to whether the carer felt their views were fully included in the support plans for the person they were supporting:

- These carers were more than 10 times more likely to report positive impacts on their finances, their capacity to continue caring, their relationship with the person they were supporting, their relationships with other family/friends, and their relationships with those paid to support the budget holder.
- These carers were more than six times more likely to report positive impacts on their quality of life, their physical and mental wellbeing, and on carers' choice and control over their own lives.

Carers' overall experience of the personal health budget process was associated with four carer outcomes, with carers four times more likely to report a positive impact on carers' relationships with those paid to support the budget holder and more than twice as likely to report positive impacts on their finances, their quality of life and their relationships with other family/friends.

In terms of carer outcomes, only carers' social lives and capacity to get/keep a paid job were not associated with any aspects of personal health budget usage or carer experiences of the personal health budget process.

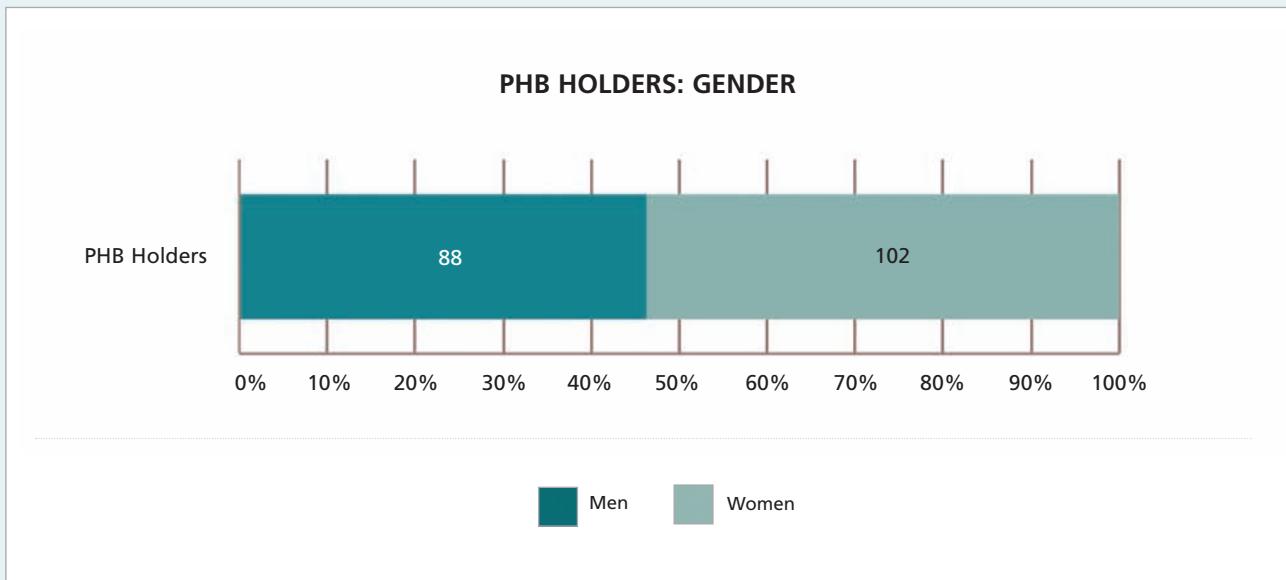
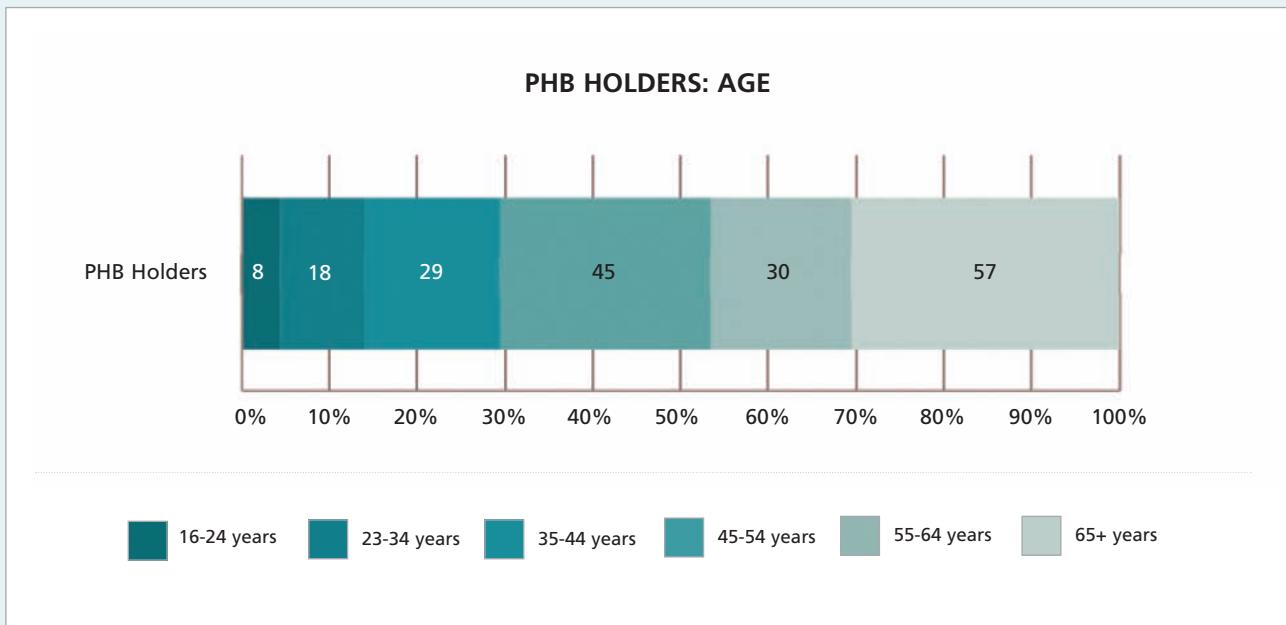
**Table 6: Personal health budget characteristics and carer experiences: Associations with positive outcomes for carers**

OUTCOME FOR CARER	Factors potentially associated with outcome: Personal health budgets and carers' experiences of personal health budgets for the person cared for					
	PHB holder more than 1 year	Social care support before PHB	Carer has carer PB	Carer knows amount of PHB for person they care for	Carer views included in PHB holders' support plan	Carer positive experience of PHB process
Finances	0.70	0.81	1.37	4.98	12.20	2.42
Support to continue caring	1.21	1.24	1.28	6.41	19.61	2.07
Quality of life	0.46	0.91	0.86	4.27	7.81	2.62
Physical and mental wellbeing	0.63	0.67	0.58	4.12	6.17	1.42
Social life	0.60	0.92	1.15	2.13	2.73	1.68
Getting/keeping paid job	1.04	1.93	0.43	2.00	1.88	1.67
Relationship with person cared for	0.61	1.34	0.97	2.76	23.81	1.71
Relationships with other family/friends	0.80	1.39	0.66	1.45	13.51	2.25
Relationships with paid supporters	1.05	3.64	1.01	3.22	18.18	4.15
Choice and control over life	0.77	1.40	1.45	3.61	6.76	1.91

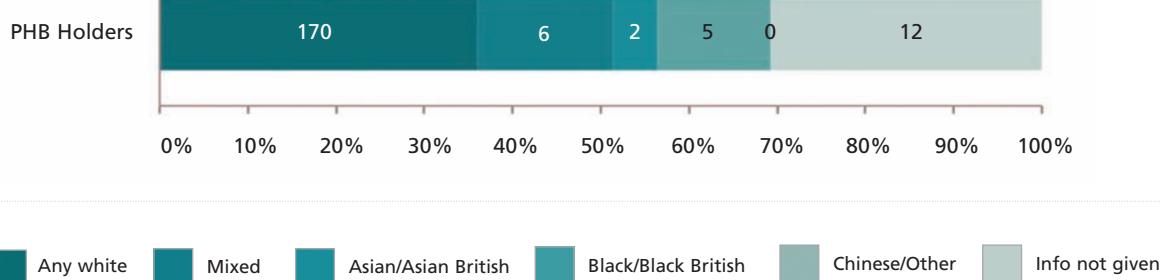
# Appendix 1:

## Personal Health Budget Holder demographic information

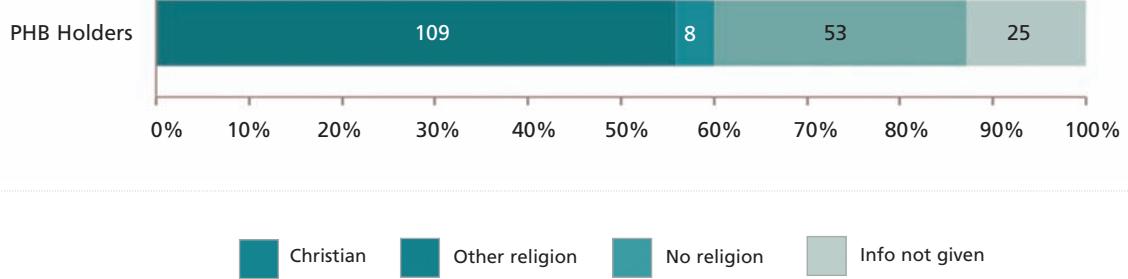
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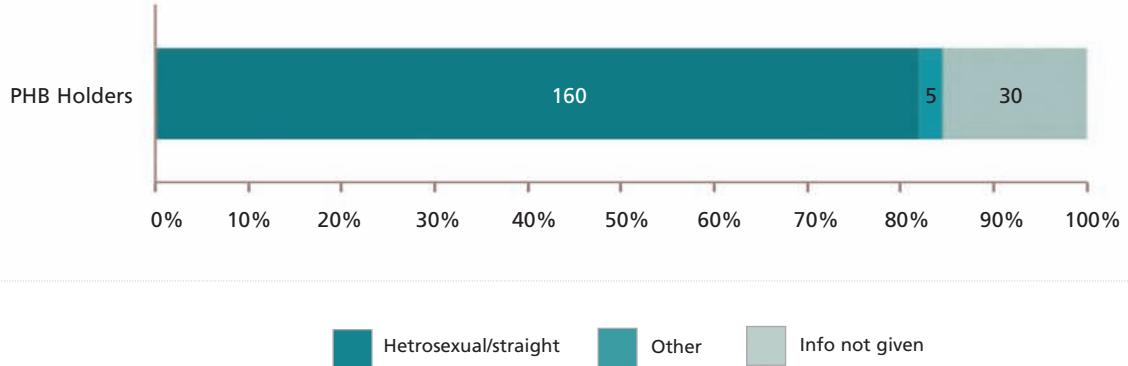
### PHB HOLDERS: ETHNICITY



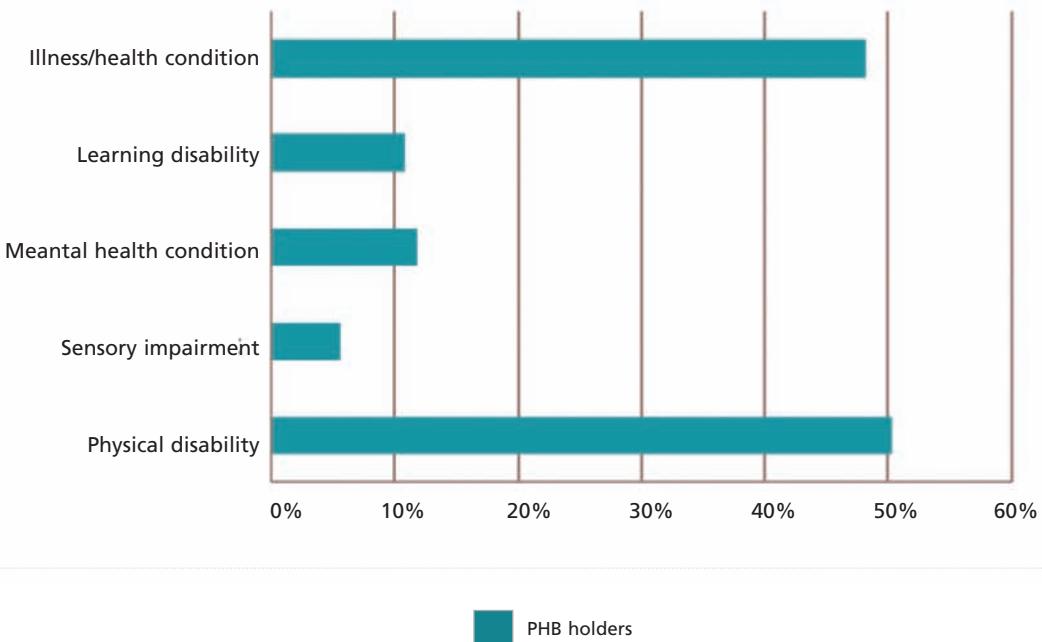
### PHB HOLDERS: RELIGION



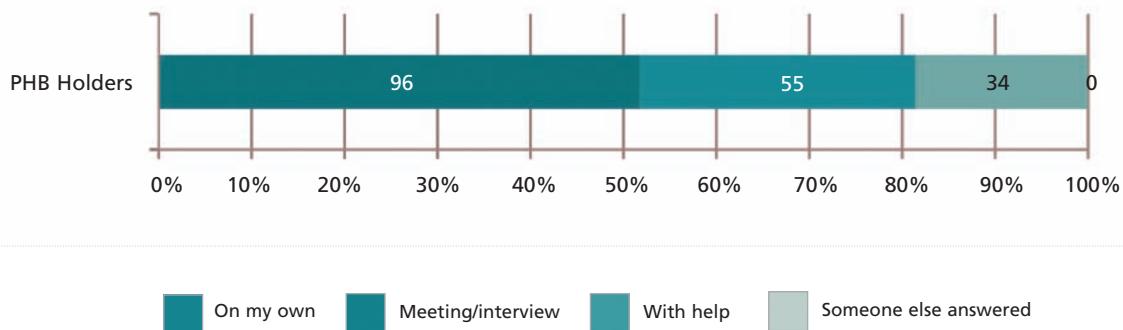
### PHB HOLDERS: SEXUAL ORIENTATION



### PHB HOLDERS: TYPE OF DISABILITY



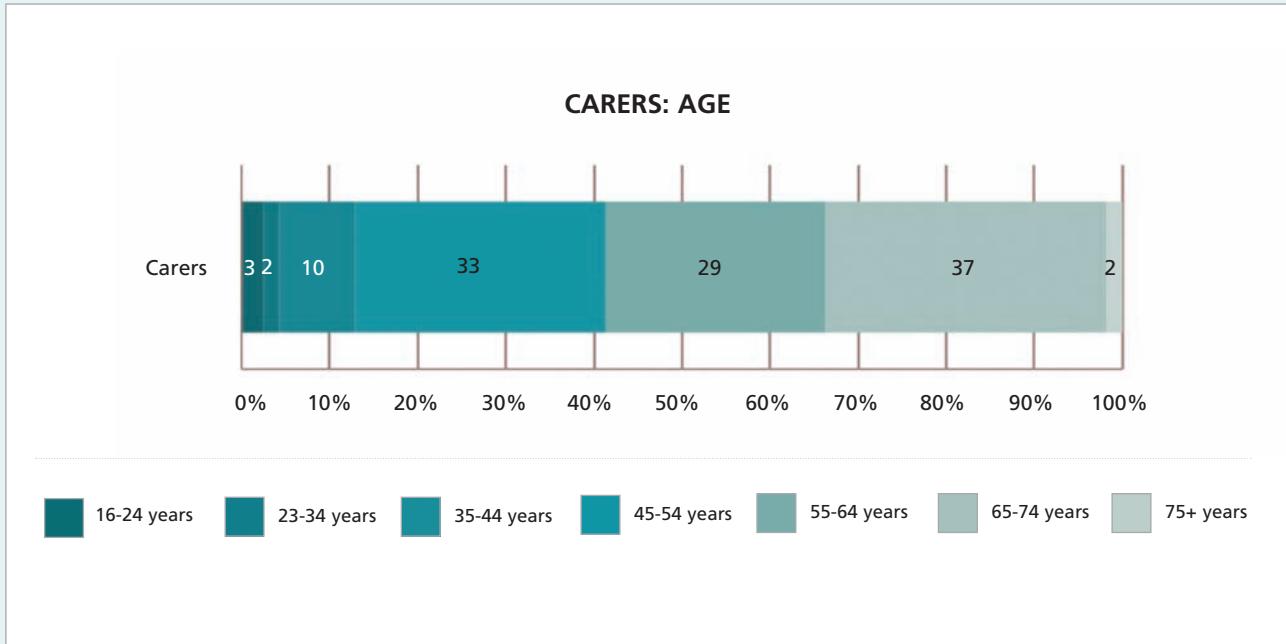
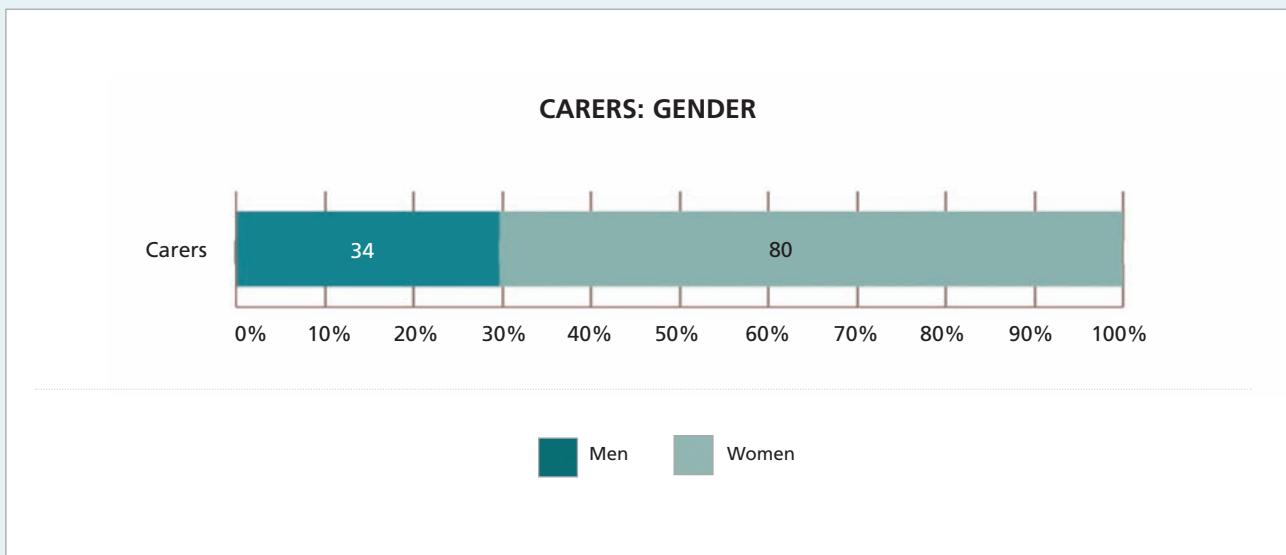
### PHB HOLDERS: HOW QUESTIONS WERE ANSWERED



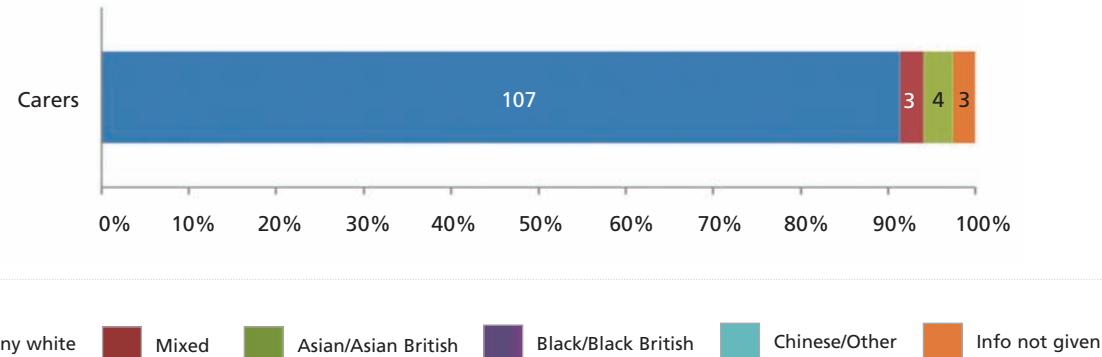
**Note:** there were only two statistically significant ( $p<0.05$ ) associations between how the questions were answered and any of the 15 outcome domains, suggesting no systematic response bias. For the outcome indicators 'Has your budget made a difference to the long-term condition for which you receive a budget?' and 'Has your budget made a difference to your relationships with your family?', people who completed the POET on their own were more likely to report the budget making a positive difference than people who completed the POET in a meeting/interview or with help from others ( $\chi^2=6.98$ ;  $df=2$ ;  $p=0.031$ ;  $\chi^2=7.00$ ,  $df=2$ ,  $p=0.030$ ).

## Appendix 2: Carer survey demographic information

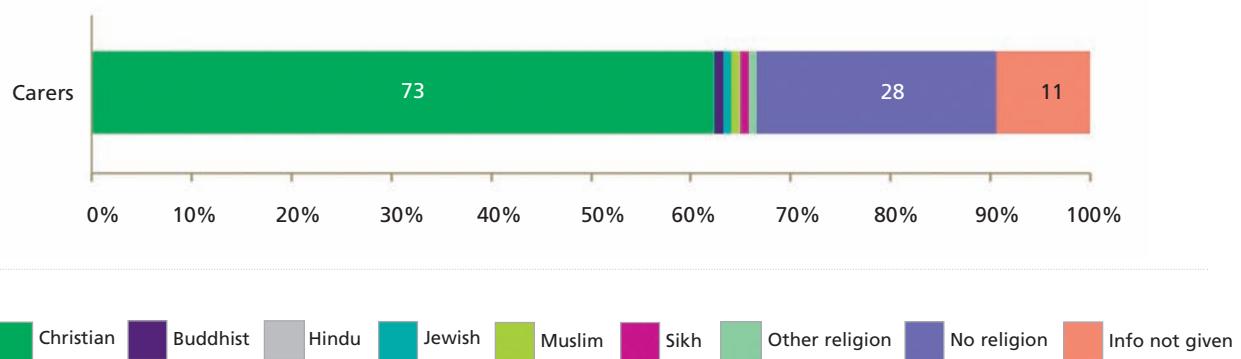
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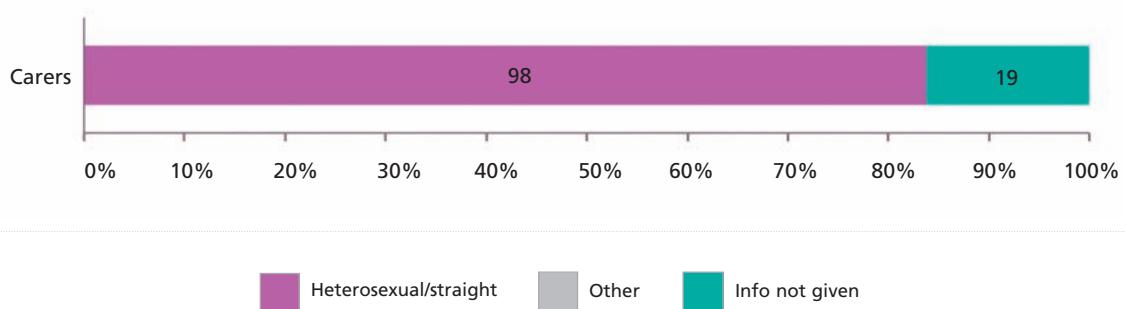
### CARERS: ETHNICITY



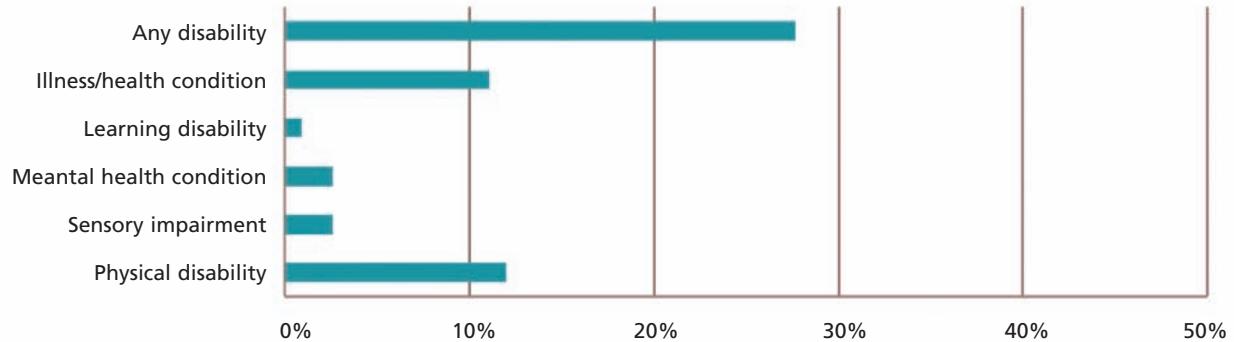
### CARERS: RELIGION



### CARERS: SEXUAL ORIENTATION



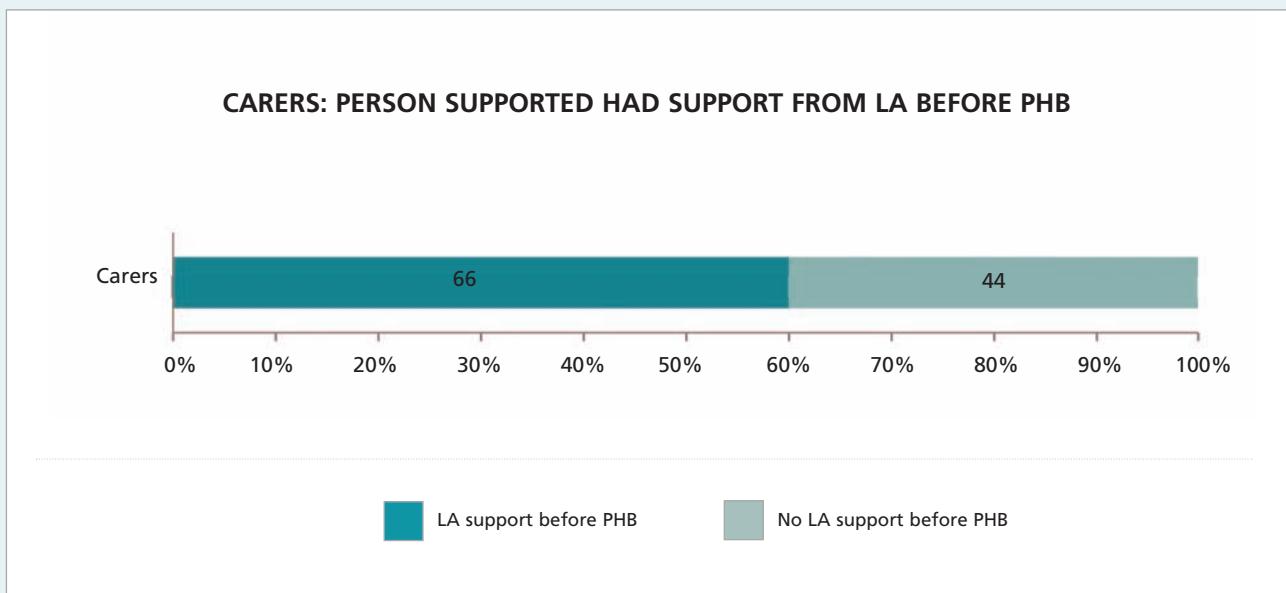
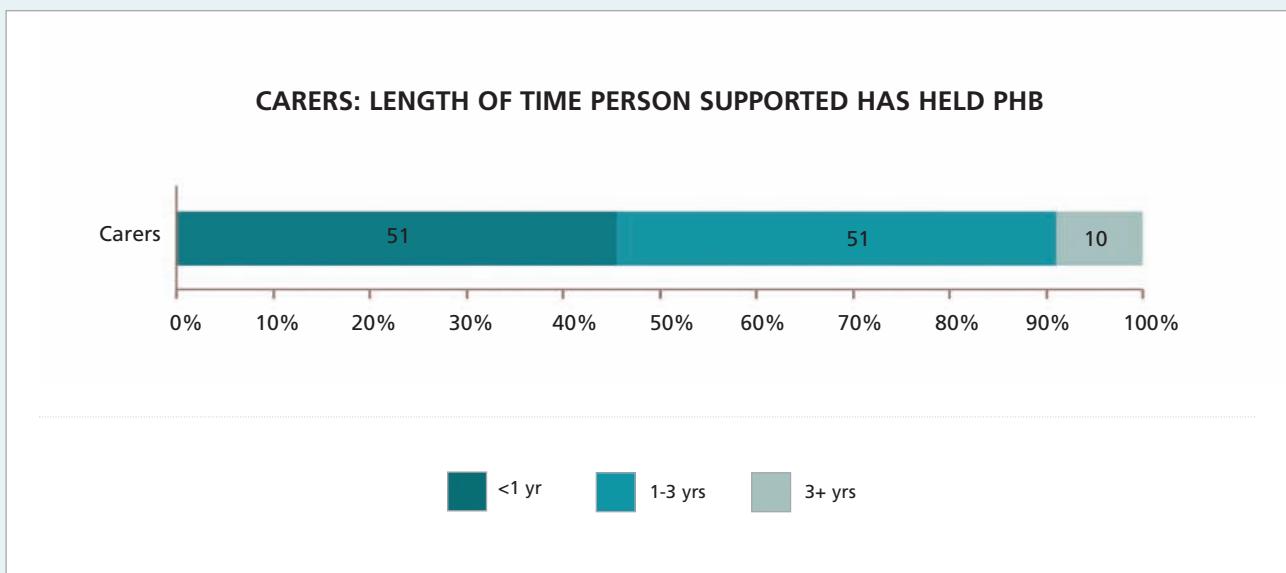
### CARERS: TYPE OF DISABILITY



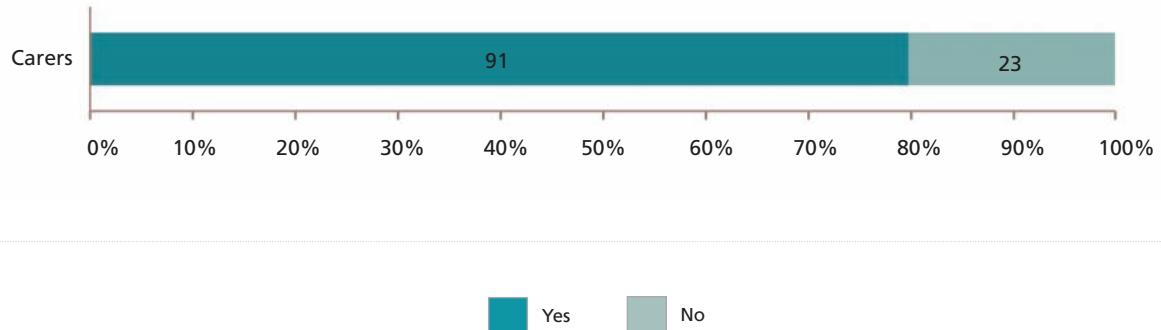
# Appendix 3:

## Carer survey: personal health budget usage & support for carers

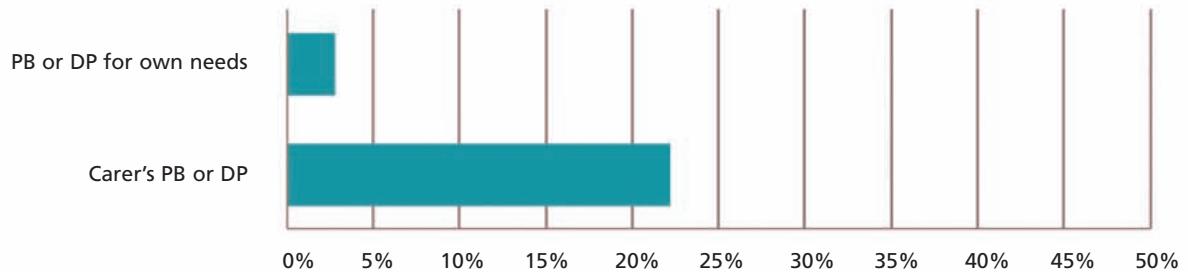
.....



### CARERS: DOES THE CARER KNOW THE AMOUNT OF THE PHB HOLDER'S BUDGET?



### CARERS: ANY PERSONAL SUPPORT FOR YOU?





**Think Local Act Personal** is a sector-wide commitment to moving forward with personalisation and community-based support, endorsed by organisations comprising representatives from across the social care sector including local government, health, private, independent and community organisations. For a full list of partners visit [www.thinklocalactpersonal.org.uk](http://www.thinklocalactpersonal.org.uk)