in Control

Lancaster University

think local act personal

THE POET SURVEYS 2014

PERSONAL HEALTH BUDGET HOLDERS AND FAMILY CARERS

POET™

Personal Outcomes Evaluation Tool

Contents

Acknowledgements

This work would not have been possible without the cooperation of the 22 participating organisations and their commitment to understanding and improving the implementation and delivery of personal health budgets. We of course would also like to give our sincere thanks to the 230 personal health budget holders and carers who took the time to complete the surveys and share their experiences.

About this document

This report has been researched and written by InControl and Lancaster University for NHS England and published by Think Local Act Personal.

Think Local Act Personal (TLAP) is a partnership established to support the positive delivery of personalisation. An important – though far from only – element of personalisation is self-directed support (SDS) via personal budgets and personal health budgets. It is therefore vital to TLAP and NHS England that we help improve delivery in these areas using data from this report. In particular, the data can be analysed to explore in more detail what can lead to improved delivery and to focus on more detailed questions including what might work best for specific groups of people. In addition to looking directly at the experience of people using personal health budgets, we will also be able to explore the experience of family carers to see what works best for them.

If you would like to know more about POET and its use across health, adults and children's services, please visit: ***www.in-control.org.uk/poet*** or email: ***poet@in-control.org.uk***

Information on personal health budgets can be found at: ***www.personalhealthbudgets.england.nhs.uk***

Information on personal budgets for people who use services, families and carers can also be found at: ***www.peoplehub.org.uk*** or by checking local council websites.

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1 INTRODUCTION

The Government has committed the NHS to rolling out personal health budgets across England. People eligible for NHS continuing healthcare now have the right to have a personal health budget. Clinical commissioning groups (CCGs) can also offer personal health budgets to others that they feel may benefit from the additional flexibility and control.

This commitment to personal budgets has been further strengthened recently by the announcement in July from NHS England for a new Integrated Personalised Commissioning (IPC) programme, which for the first time will blend comprehensive health and social care funding for individuals, and allow them to direct how it is used.

The introduction of personal health budgets to the NHS and the new IPC programme represents a potentially powerful innovation and power shift, as they allow individual patients the opportunity to direct resources previously managed by professional commissioners. The intention is to improve individual choice and control and to ensure patients receive support and services that are tailored to their own individual needs and circumstances. This more personalised approach is ultimately intended to be more cost effective and lead to better outcomes.

Over the past 10 years, In Control together with the Centre for Disability Research at Lancaster University has been developing the Personal Outcomes Evaluation Tool (POET) to measure the outcomes of personal budgets and personalised care and support, and the impact they are having on people's lives. POET was initially developed for use in adult social care, and then in health and it is currently being piloted in children's services.

By consistently measuring both process conditions and outcomes, POET is able to produce a data set that will identify the critical process conditions that CCGs, local authorities and partner agencies need to establish if they are to maximise the efficiency and effectiveness of personal health budgets. POET provides the opportunity for national reports, as well as local reports to support organisations to benchmark and review their own performance, to benefit from a shared understanding of the critical conditions for successful implementation of personal health budgets, and to inform action planning for improvement.

Two national reports (2011 and 2013) have been published by Think Local Act Personal (TLAP) looking at people's experiences in adult social care, detailing the impact of personal budgets on more than 5,000 people[1], and a third national report will be published in autumn 2014.

A version of the POET tool has also been used to understand the experience of disabled children and their families who have a personal budget and/or an education, health and care plan (EHC); the initial findings in this area were published in July 2014[2]. In total, more than 8,000 people across health, adult social care, and children's services have shared their experiences using POET.

This latest report includes data from 129 personal health budget holders and 101 carers of people in receipt of a personal health budget from 22 different NHS and council organisations in 13 areas, and builds on our previous survey of personal health budget recipients.

1 *Hatton C & Waters J (2011), Think Local Act Personal, Hatton C & Waters J (2013) The National Personal Budget Survey THE SECOND POET SURVEY OF PERSONAL BUDGET HOLDERS AND CARERS, Think Local Act Personal www.thinklocalactpersonal.org.uk/_library/POETNationalReport_121113.pdf*

2 *Hatton C & Waters J (2014) Measuring the outcomes of EHC plans and personal budgets, In Control www.in-control.org.uk/ehcpoetreport*

2 KEY FINDINGS

The surveys showed positive outcomes for people with a personal health budget and their carers in the following areas:

- Independence (77%)
- Quality of life (86%)
- Relationships with family (69%)
- Choice and control (70%)

Carers also reported positive outcomes in the following areas:

- Being able to continue caring (90%)
- Quality of life (86%)

Very few people (between 0% and 5.4%) reported negative outcomes and responses indicate personal health budgets worked well for people regardless of their age. Those people who reported worse health tended to report better outcomes.

However what is clear from the findings is the need to improve the experience of control of a personal health budget.

The personal health budget process was reported as difficult by a substantial minority of people (11.9% to 22%).

The process experience was also strongly associated with good outcomes, particularly in these areas:

- Views being taken into account in care planning and setting budgets
- Process being easy
- Having support to plan

Very few people reported negative outcomes

3 BACKGROUND

For personal health budgets, a previous iteration of the tool was first used with recipients of personal health budgets and their carers in 2013 and reported the experiences of 300 people. TLAP published these results which demonstrated the experience of people who had a personal health budget and their families in the first six months following the end of the Department of Health pilot programme.

A year later the current version of POET has been used to provide data for this report. The POET survey used in this report has been updated to look more closely at areas of the personal budget process that appeared from previous work to be strongly associated with good outcomes, in particular the extent to which people feel their views have been included in the personal health budget process. The updated version of POET is being used across both health and adult social care, although this report includes only the experiences of holders and carers of people with personal health budgets.

The POET survey tools for this project gathered views and experiences of personal health budget holders and their (mainly family) carers separately. The tools were designed to measure how well organisations are implementing personal health budgets and to what effect.

Specific questions investigate people's experience of the 'personal health budget process' and their report of the impact (or not) 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 makes POET unique.

Conceptually, POET has been designed to generate 'practice-based evidence'. 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.

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?

Although the implementation of personal health budgets is still at a relatively early stage and consequently the number of respondents to the survey is small, we still hope to explore 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[3].

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.

Whilst the report contains some interesting findings that point towards good practice, it is important to bear in mind the numbers in the survey were too small to make firm conclusions on which approaches work best.

3 *Barkham, M. and& 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. Glasby, J. & Beresford, P. (2006). Who knows best? Evidence-based practice and the service user contribution. Critical Social Policy, 26, 286-284.*

4 RESEARCH ETHICS

Because the POET surveys were designed for people to evaluate their experiences of existing personal health budgets, the surveys are service evaluation rather than research according to guidance from the National Research Ethics Service[4], and therefore did not require Research Ethics Committee approval.

All formats of both POET surveys explained how the information would be used. Anonymity and individual confidentiality were guaranteed as 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, 129 personal health budget holders and 101 carers completed the POET survey and gave their agreement for the information to be used. Personal health budget holders identified 10 different NHS organisations as providing their personal health budget. Eighty-five personal health budget holders said their budget had been allocated to them by the NHS, 13 by their local council, 16 by both, 10 did not know. Carers identified 21 different organisations as providing their personal health budget, 17 NHS organisations and four local councils. Seventy-two carers said their budget had been allocated to the person they care for by the NHS, 10 by their local council, 11 by both, eight did not know.

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

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

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

129 personal health budget holders and 101 carers completed the POET survey

5 THE POET SURVEYS

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

The POET survey for personal health budget holders contained the following questions:

- 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) or not across 15 aspects of the person's life.
- Information on people's self-rated assessment of their current general health.
- Information about the extent to which personal health budget holders felt their views had been included in various aspects of the process.
- Equalities monitoring questions (gender, age, disability, ethnicity, religion, sexual orientation).
- Space for people to write in their opinions on personal budgets.

The POET survey for carers contained the following questions:

- Information about who carers are caring for and how much care they provide.
- Information about the personal health budget held by the personal budget holder.
- The extent to which carers felt their views were included in various aspects of the process.
- Information about whether the personal health budget holder's budget has made a difference (either positive or negative) across eight aspects of the carer's life.
- Information on carers' self-rated assessment of their current general health.
- Equalities monitoring questions (gender, age, disability, ethnicity, religion, sexual orientation).
- Space for people to write in their opinions on personal budgets.

6 MAIN FINDINGS: PERSONAL HEALTH BUDGET HOLDERS

A large majority of respondents who provided information were white (85%) with half of respondents being male (50.9%); respondents represented a broad adult age range.

Personal health budget holders reported a wide range of reasons for which they held their budget, most commonly physical disability (30.4%), complex health needs (28.8%), a mental health condition (12.3%), substance misuse (8.8%), learning disabilities (4.4%) or being an older person (4.4%).

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 (20.8%) 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 more than a third (42.4%) 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 how personal health budgets were managed: People responding to the POET survey most commonly managed their personal health budget through direct payments paid to them (44.8%), followed by direct payments to a friend or family member (27.2%). Less common were budgets held by service providers (11.2%), council or NHS-managed personal health budgets (8%), or service brokers (8%).

Men were more likely than women to manage their budget in the form of a direct payment paid to them[5]. People aged under 65 were more likely than people aged 65 or over to manage their budget via a service broker[6] or to have them managed by the council or NHS[7]. The type of personal budget people had was not related to people's self-rated health.

5 *Fisher's exact p=0.020).*
6 *Fisher's exact p=0.022*
7 *Fisher's exact p=0.044*

A majority of personal health budget holders (60.1%) were able to provide the cost of their personal budget as a weekly support cost (42.6%) or a one-off payment (18.6%). A small number (11.6%) said they did not know the amount of their personal budget.

Of the 54 people (41.9%) reporting a weekly amount for their personal budget: a quarter (25.9%) reported a budget up to £200 per week; slightly more (29.6%) between £201 and £500 per week; slightly fewer (18.6%) between £501 and £1,000 per week; and a further quarter (25.9%) over £1,000 per week.

Of the 24 people (18.6%) reporting a one-off payment: more than a third (37.5%) reported a one-off payment up to £1,000; a third (33.3%) a payment between £1,001 and £2,000; and less than a third (29.2%) a payment above £2,000.

One third of people got help in planning how to use their personal health budget from the NHS (32.9%), the same as had help to plan from their family/friends (32.9%).

One third of people got help in planning how to use their personal health budget from the NHS

Fewer people had help to plan from a provider (10.1%), the council (7.6%), or a broker (7.6%). A small number (8.2%) said they had no help to plan.

Respondents reported a wide range of experiences in relation to their views being included in different aspects of the personal health budget process. The overwhelming majority of respondents felt that their views had been taken into account in their assessment (90.7%) and in the planning process (84.2%). A lower proportion, although still a majority (71.3%), said their views had been taken into account when the budget was set.

Respondents also reported a range of experiences in relation to how easy various aspects of the personal health budget process was for them.

About half of respondents who said that the question was applicable to them, reported that it was easy to understand the restrictions on how they could spend their personal health budget (51.8%), choose support (51%), get support (50%) and agree the budget (50%).

Less than half of respondents who said that the question was applicable to them, reported that it was easy for them to get information and advice (45%), plan their support (47.3%), account for how the budget was spent (46.7%) or manage their support (41.6%).

One third of respondents who said that the question was applicable to them, reported that it was easy for them to change their support (33.7%).

The personal health budget process was reported as difficult by a substantial minority of people (11.9% - 22%) who said that the question was applicable to them.

IN TERMS OF THE IMPACT (OR NOT) OF PERSONAL HEALTH BUDGETS ON PEOPLE'S LIVES:

More than 80% of personal health budget holders who said that the question was relevant to them, reported their budget having a positive impact on their quality of life (86.6%) and arranging their support (82.1%).

More than 70% of personal health budget holders who said that the question was relevant to them, reported their budget having a positive impact on: their self-esteem (72.6%), feeling safe (70.0%), being independent (77.7%), having control over their life (70.9%) and dignity in support (71.6%).

More than 60% of personal health budget holders who said that the question was relevant to them reported their budget having a positive impact on: their relationships with people paid to support them (68.4%), friendships (63.8%), family relationships (69.6%), their mental health (69.6%) and their physical health (64.9%).

Fewer personal health budget holders who said that the question was relevant to them, reported a positive impact of their budget on: choosing where and with whom they lived (48.2%) and volunteering (50%). Very few people reported a positive impact on keeping a paid job (17.9%). In these areas of lower impact on life most people reported their personal health budget making no difference.

Small numbers of people (between 0.9% and 5.5%) reported their personal health budget having a negative impact on any of the 15 aspects of people's lives.

People used their personal health budgets in a variety of ways; to buy care and support services (35.2%), to access personal assistants (25.5%), to access community or leisure services (20.4%) and to buy equipment (19.0%).

FACTORS ASSOCIATED WITH PEOPLE REPORTING A POSITIVE IMPACT:

Personal health budgets worked for people across the whole age range of people surveyed and it was found that outcomes were not related to age. Furthermore, it was found that the way the budget was managed, did not strongly affect the results.

People who felt that their views had been included when their needs were assessed, and also in deciding the amount of their budget, were however more likely to report good outcomes.

Access to help with support planning was also associated with better outcomes. People who planned their support themselves without any help were less likely to report good results.

People who said that it had been easy to get information and advice, and to arrange support were more likely to report better outcomes.

People with poorer self-reported health; people getting some form of help in planning their budget; people who reported their views were fully included in their needs assessment, the setting of the amount of the budget and developing the support plan; and people who reported each aspect of the personal health budget process being easier, were all more likely to report a positive impact of their budget on a range of areas of life.

7 DETAILED FINDINGS: PERSONAL HEALTH BUDGET HOLDERS

Who responded to the POET survey?

As previously mentioned in this report, a total of 129 personal health budget holders completed the POET survey and gave their agreement for the information to be used. As people could choose not to complete particular questions within the survey, percentages are of the total responding to that particular question. In some areas, respondents were asked to indicate if a particular question was not relevant to them.

Equalities monitoring information shows:

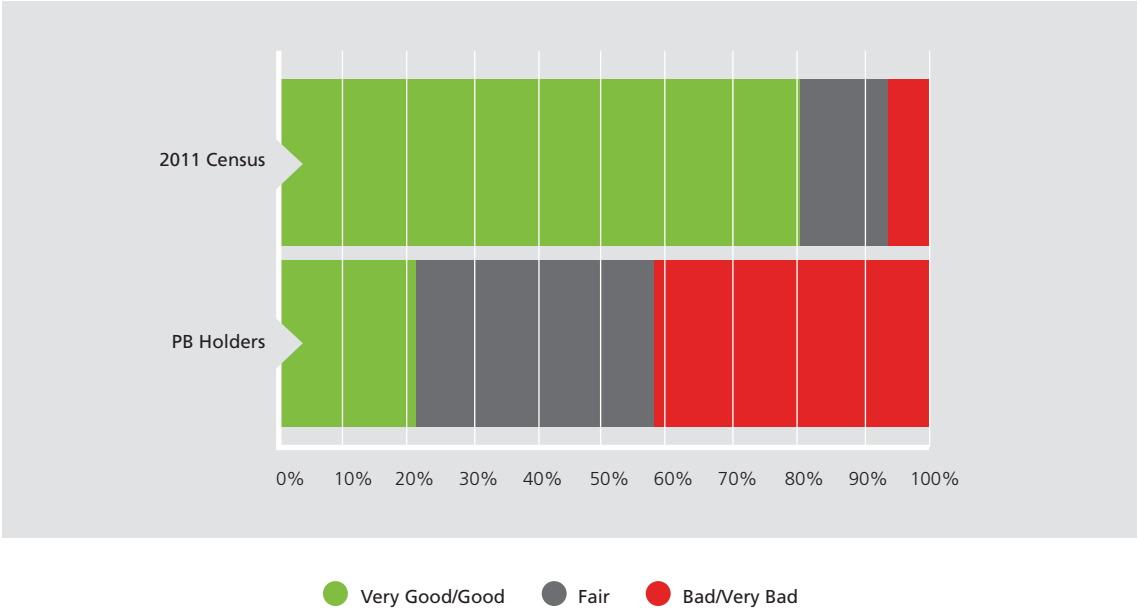
- Just under half of personal health budget holders (46.0%) answered the POET survey on their own, nearly a quarter (23%) of people said they had some help from another person to complete the survey. A small number completed the survey in a meeting or interview (13.3%), and some of the surveys returned were completed by someone else on behalf of the personal budget holder (17.7%).
- Respondents were equally divided by gender – half of respondents (50.9%) were men.
- In terms of age, almost a third (32.4%) of personal health budget holders were aged 16-44 years, people were most commonly (40.7%) aged 45-64 years, and just over a quarter (26.9%) were aged 65 years or over.
- A vast majority of respondents were White (85.3%), with a minority of people from other ethnic groups (14.7%).
- More than half of respondents were Christian (53.5%), with a third (33.7%) of respondents reporting themselves to have no religion.
- A large majority of respondents reported themselves to be heterosexual/ straight (80.2%).

The POET survey for personal health budget holders also asked people to state the main reason for which they were getting a personal health budget. Nearly a third said they had complex health needs (28.8%) or a physical disability (30.4%). The rest of the responses were from people stating the main reason for them getting a personal health budget was mental health difficulties (12%), substance misuse (8.8%), learning disability (4%), being an older person (4%) or another reason (12%).

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

Finally, we asked the same question used in the 2011 Census concerning people's self-rated general health over the past 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[8]. Less than a quarter (20.8%) of personal health budget holders reported their health as good or very good, compared to over three-quarters (81.4%) of the general population, and more than a third (42.4%) of personal health budget holders reported their health as bad or very bad compared to 5.4% of the general population.

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



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

How are people using personal health budgets?

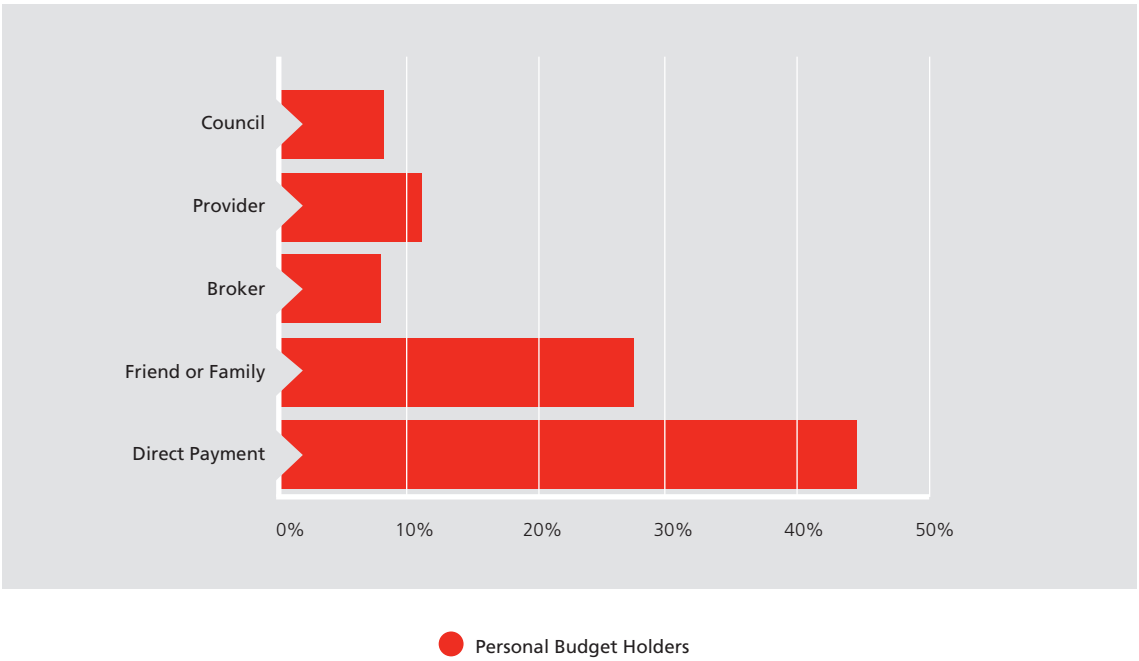
The POET survey asks personal health budget holders several questions about how they are managing personal health budgets and what support people have had throughout the personal health budget process.

We also checked for any differences in personal health budget usage and support by gender, age band (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 (44.8%%), followed by direct payments looked after by a friend or family member (27.2%). Personal health budgets managed by a provider (11.2%), council or NHS-managed personal health budgets (8%) and personal health budgets managed by a broker (8.0%) were less common.

FIGURE 2: Management of personal health budgets



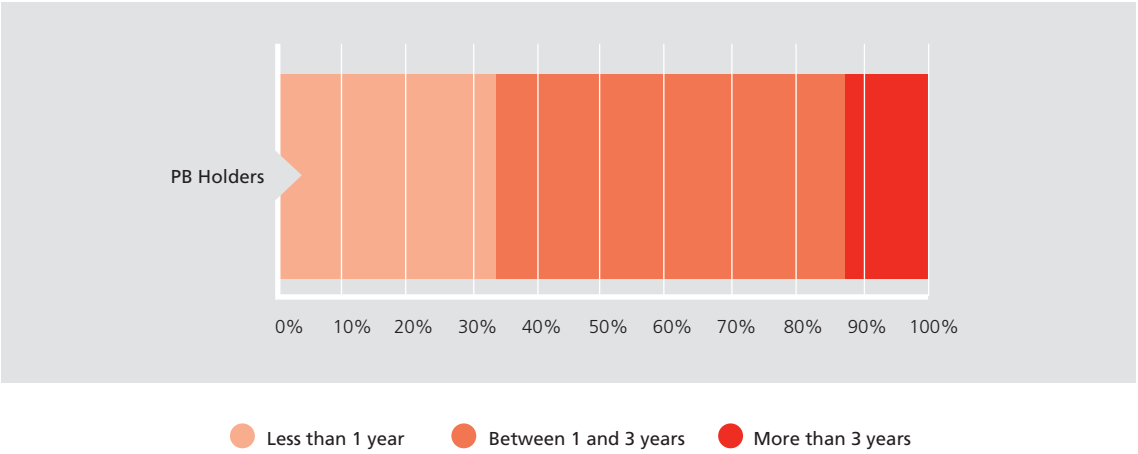
Men were more likely than women to manage their budget in the form of direct payments paid to them[9]. People aged under 65 were more likely than people aged 65 or over to managed their budget via a service broker[10] or to have them managed by the council or NHS[11]. The type of personal budget people had was not related to people's self-rated health.

HOW LONG HAVE PEOPLE HELD A PERSONAL HEALTH BUDGET?

Figure 3 shows how long POET survey respondents have held their personal health budget. Overall, just over half (52.8%) of respondents had held their personal budget between one and three years, just under a third (32.0%) for less than a year, and relatively few (12.8%) for more than three years.

There were no differences in the length of time people had held a personal health budget by gender, age or self-reported health status. People managing their budget via a direct payment paid directly to them were more likely than other budget holders to have held their budget for either less than one year or for more than three years[12]. There were no other associations between type of budget and length of time the budget had been held or the type of personal health budget people held.

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



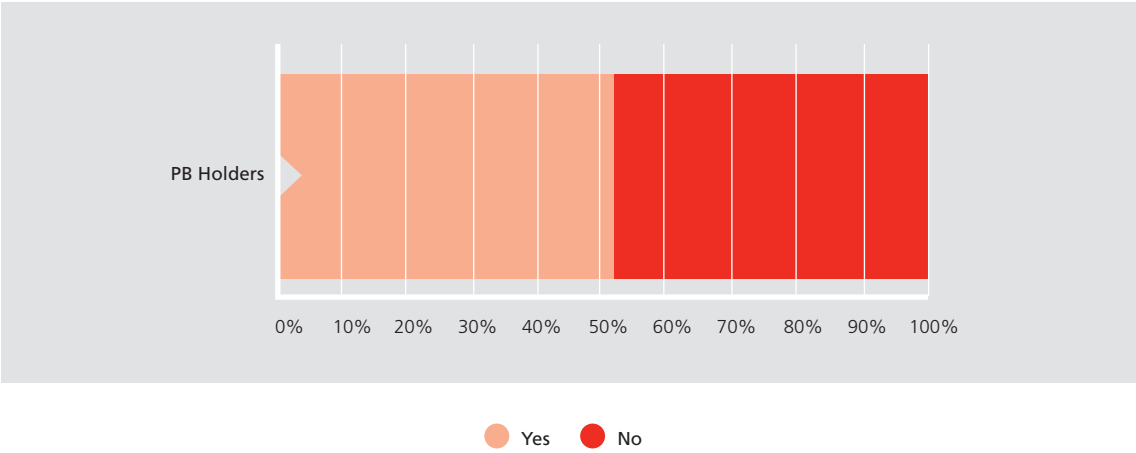
9 *Fisher's exact p=0.020*
10 *Fisher's exact p=0.022*
11 *Fisher's exact p=0.044*
12 *chi-square=12.84; df=2; p=0.002*

DID PEOPLE GET A SERVICE OR PAID SUPPORT BEFORE THEIR PERSONAL HEALTH BUDGET?

Figure 4 shows how many personal health budget holders had been receiving help from someone who was paid to support them before getting their personal budget. Overall, just over half (51.2%) of respondents had been receiving social care support before the start of their personal health budget.

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

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



THE COST OF PERSONAL BUDGETS

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

Overall a majority of personal health budget holders (60.9%) reported having been told their weekly support costs or amount of one-off payment. There were no statistically significant differences in whether people had been told their support costs or not by gender, age, self-reported health status or type of personal budget.

FIGURE 5: Amount of money in personal health budgets

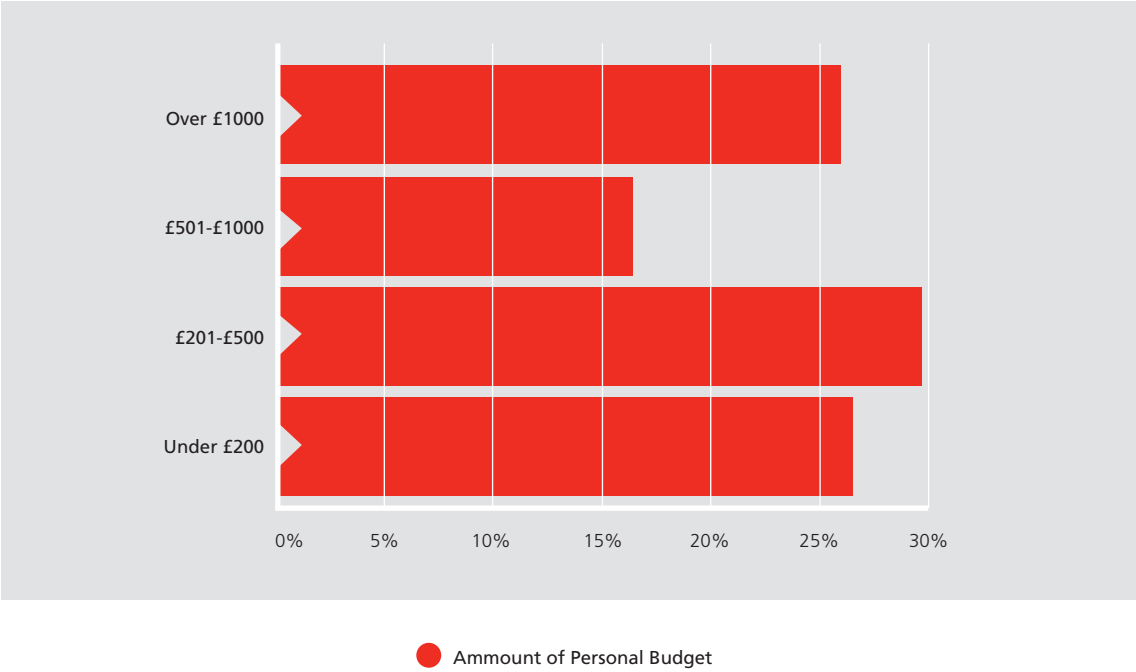


Figure 5 shows that of the 54 people (41.9%) reporting a weekly amount for their personal budget: a quarter (25.9%) reported a budget up to £200 per week; slightly more (29.6%) between £201 and £500 per week; slightly fewer (18.6%) between £501 and £1,000 per week; and a further quarter (25.9%) more than £1,000 per week.

Of the 24 people (18.6%) reporting a one-off payment: more than a third (37.5%) reported a one-off payment up to £1,000; a third (33.3%) a payment between £1,001 and £2,000; and less than a third (29.2%) a payment more than £2,000.

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

SUPPORT FOR PLANNING PERSONAL HEALTH BUDGETS

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

Figure 6 shows how many people used various sources of support in planning how to use their personal health budget, respondents could indicate they had support from more than one source. The two main areas of support were from the NHS (40.3%), and from family or friends (41.3%), with support to plan from other areas also available to some people, providers (12.4%), brokers (9.3%). 10.1% of people said they had no help to plan.

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

- People with a direct payment paid directly to them were more likely to do their planning themselves without any help[13].
- People with a direct payment managed by a friend or family member were more likely to get help with planning from family or friends[14].
- People with a direct payment managed by a broker were more likely to get help with planning from the council[15].
- People with a budget managed by a provider were more likely to get help with planning from family or friends[16] and also from an independent person[17].
- People with a budget managed by the NHS or council were more likely to get help with planning from a service provider[18]

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

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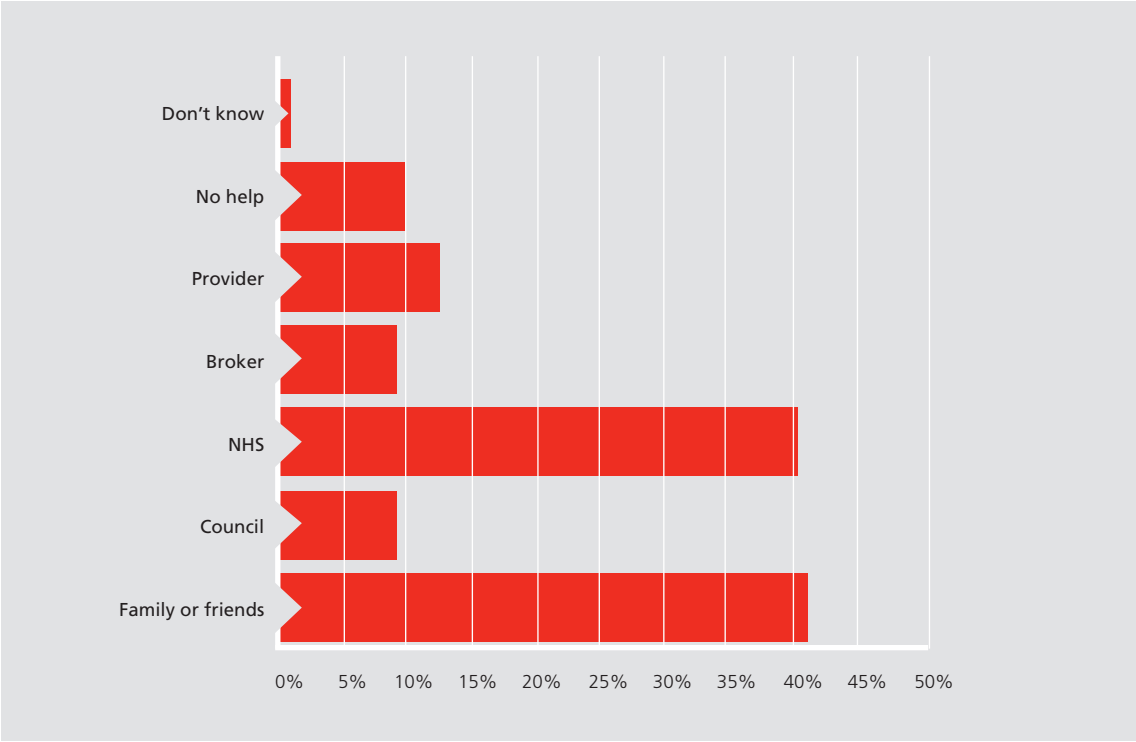
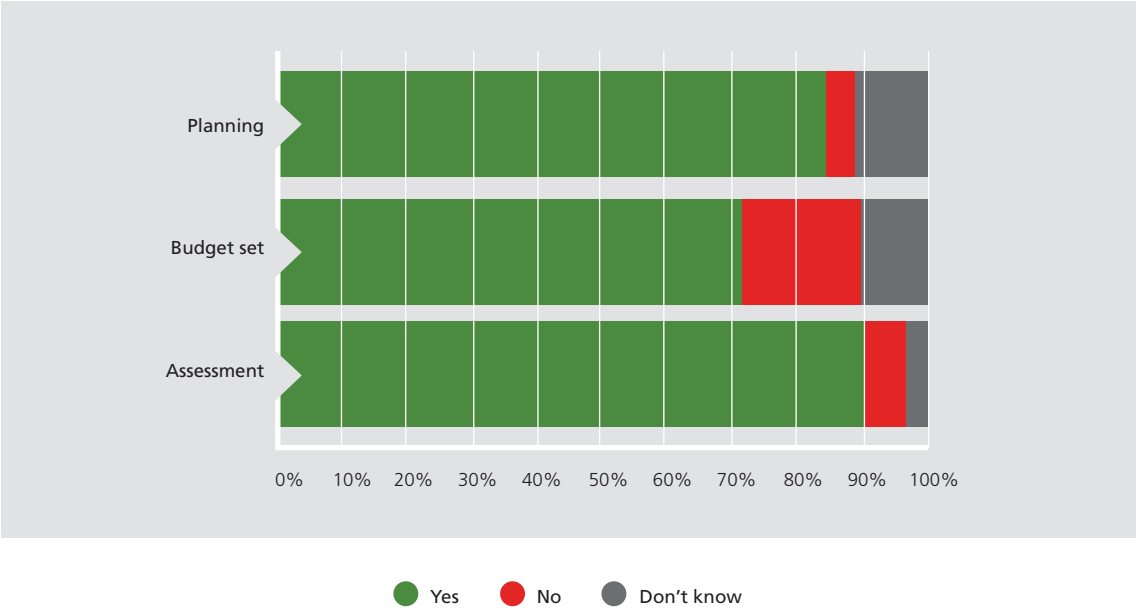
13 *Fisher's exact p=0.038*
14 *Fisher's exact p<0.001*
15 *Fisher's exact p=0.005*
16 *Fisher's exact p=0.019*
17 *Fisher's exact p=0.014*
18 *Fisher's exact p<0.001*

FIGURE 6: Support for planning personal health budgets



Finally, the POET survey asked respondents whether their views were included in various aspects of the personal health budget process (see Figure 7). The overwhelming majority of personal health budget holders reported their views had been included when their needs were assessed (90.7%) and when their plan was developed (84.2%); a less substantial majority reported their views had been included when their budget was set (71.3%).

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



WAS THE PERSONAL HEALTH BUDGET PROCESS DIFFICULT FOR PEOPLE?

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

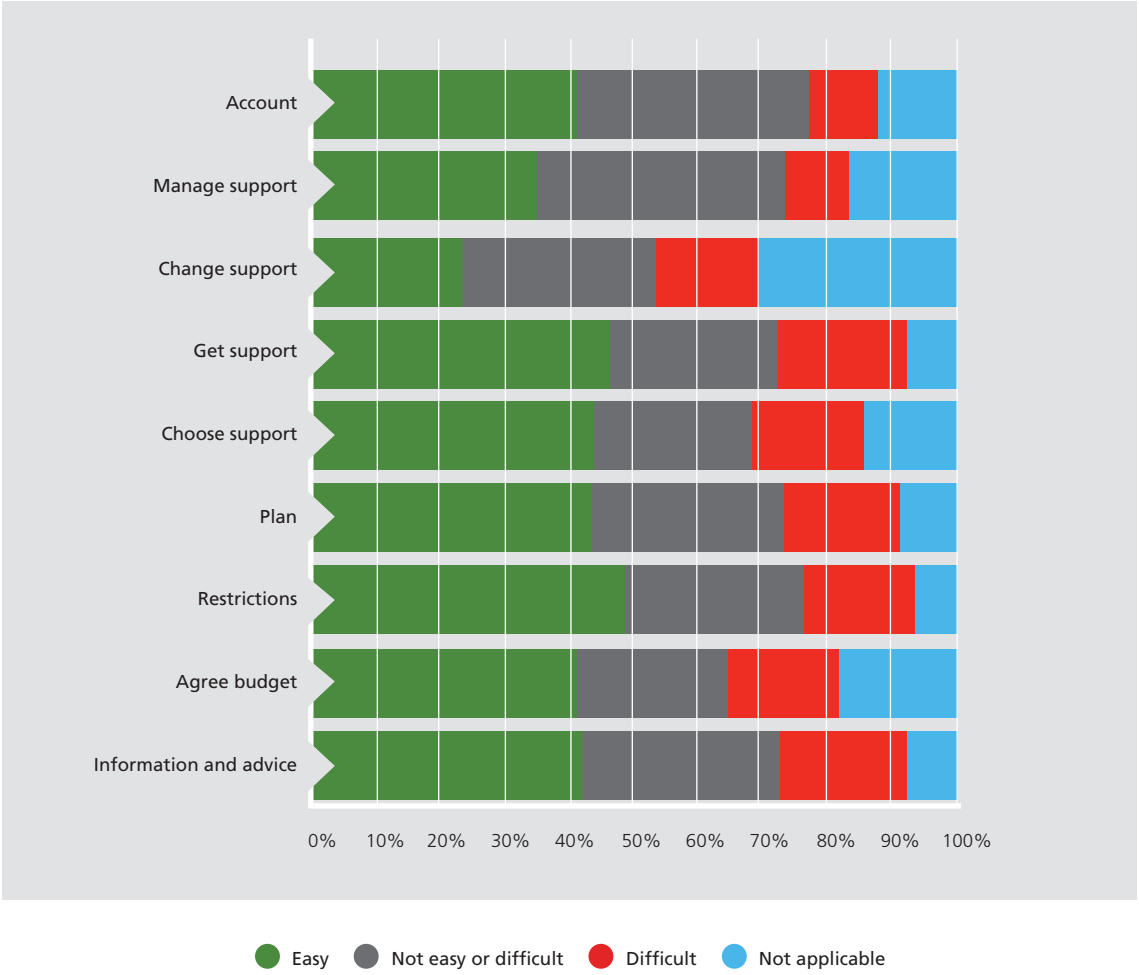
As many people's budgets were of relatively short duration and/or made as one-off payments, it is possible that not all of these questions would have been relevant to all respondents at the point in time they completed the survey. Respondents were given an option to say if an area of the process being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

Around 20% of personal health budget holders said that aspects of the process were difficult for them in six of nine areas we asked about: Information and advice (20%); Agreeing the budget (21.4%); Developing a plan (20%); Choosing support (20.2%); Getting support (21.4%); and Making changes to support (22.9%).

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

People with a direct payment paid directly to them were more likely to report that it was easy for them to manage their support[19] and get the support they wanted[20]. People with a direct payment managed by a broker were more likely to report that it was easy to change their support[21]. There were no other differences according to personal budget type. There were also no differences according to people's age or gender.

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



19 *Fisher's exact p=0.049*
20 *Fisher's exact p=0.004*
21 *Fisher's exact p=0.028*

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

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

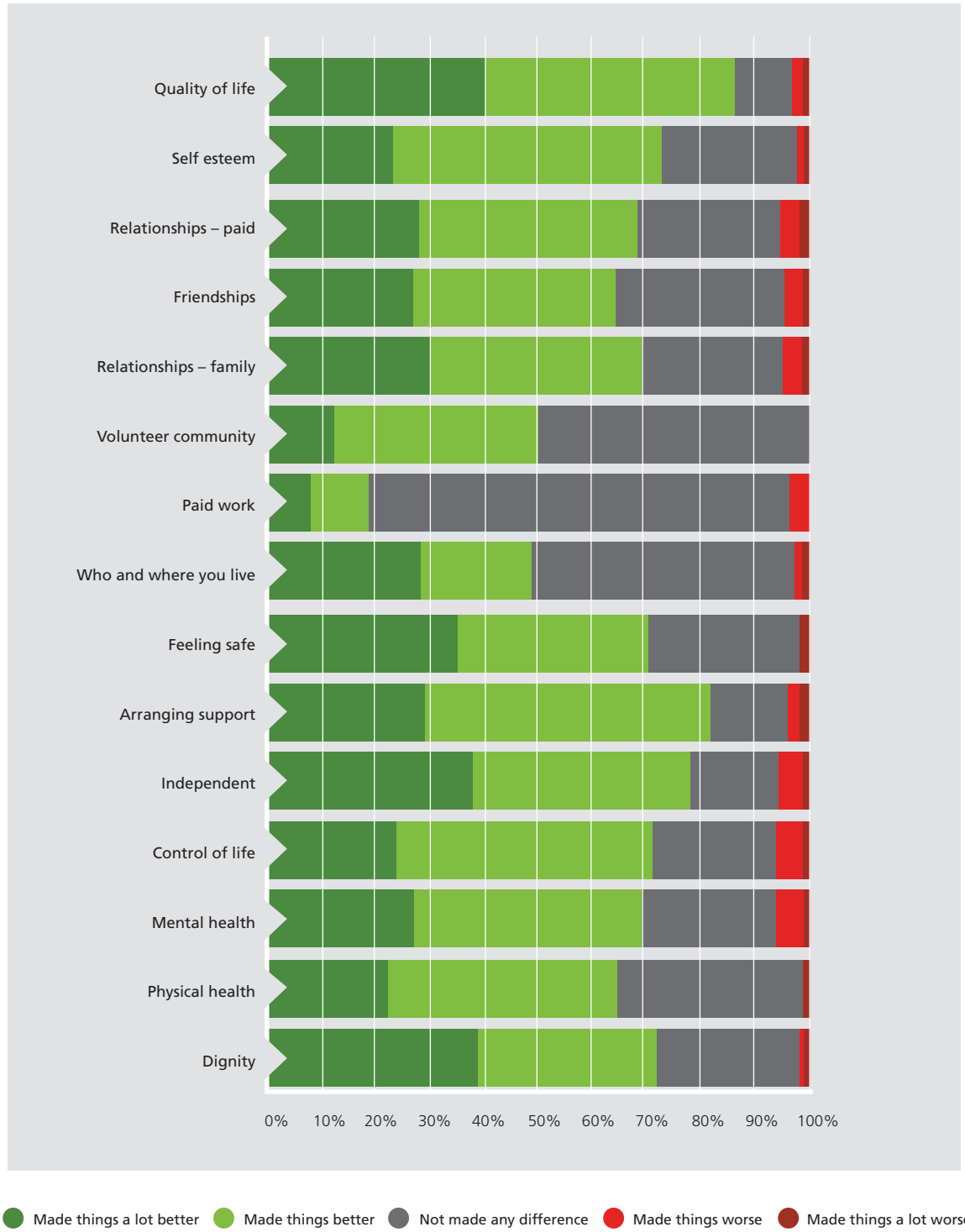
Overall, more than 80% of personal health budget holders reported their budget having a positive impact on their quality of life (86%) and arranging support (82.1%).

More than 70% of personal health budget holders reported their budget having a positive impact on their self-esteem (72.6%), feeling safe (70%), independence (77.7%), control over life (70.9%) and dignity (71.6%).

More than 60% of personal health budget holders reported their budget having a positive impact on their relationships with people paid to support them (68.4%), friendships (63.8%), family relationships (69.6%), physical health (64.9%) and mental health (69.6%).

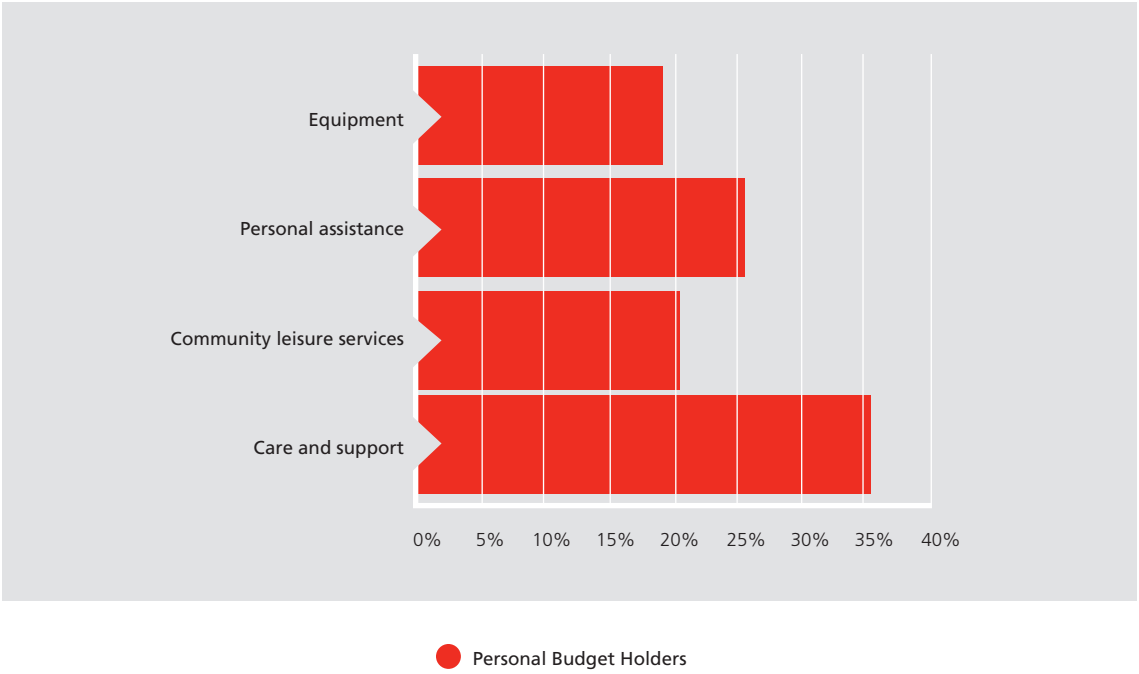
Overall, small numbers of people (between 0% and 5.4%) reported their personal health budget having a negative impact on any of these 15 aspects of people's lives.

FIGURE 9: Outcomes of personal health budgets



Finally, we asked personal health budget holders how they had used their personal health budget, specifically whether the budget had been used for: care and support, community and leisure services, a personal assistant, or equipment. People could choose more than one option. Figure 10 below shows that significant numbers of personal health budget holders used their budget in all these ways. The most common way to use their budget was on care and support services (35.2%), followed by a personal assistant (25.5%), community and leisure services (20.4%), and for equipment (19%).

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



WHAT WORKED WELL, WHAT DIDN'T AND WHAT WOULD PERSONAL HEALTH BUDGET HOLDERS' CHANGE?

Respondents were asked to comment about their experience of having a personal health budget. We asked people what worked well, what didn't work well and what specific changes they would make. Three quarters of people commented on what had worked well (76%), more than half commented on what had not worked well (60.5%), and a third made comments suggesting changes.

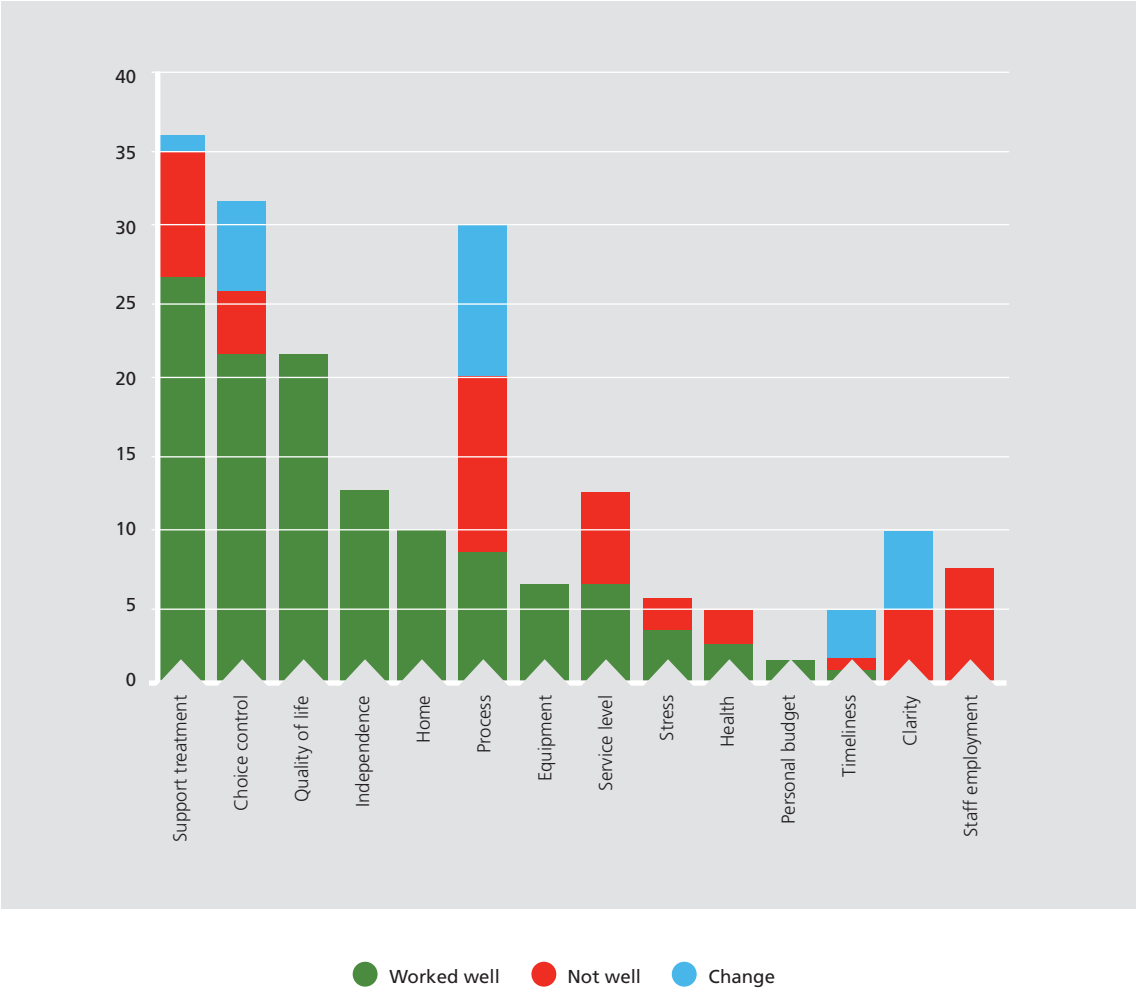
The length of response varied from a couple of words to several sentences, with most people providing just a single sentence. Responses tended to illustrate people's experience of the process of taking control of a personal health budget or the impact the personal budget had on their life.

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

When POET has been used previously respondents have been asked to comment on their experience of having personal budgets. Gathering and reviewing free text responses from personal budget holders by ongoing use of the POET has allowed us to identify several themes that commonly feature in the responses people provide. These themes were used to categorise and quantify the responses people provided in this personal health budget survey. Responses that did not fit the established themes were then reviewed and categorised to identify areas that people talked about in this survey where they had not previously. The categories overleaf summarise the issues and themes people wrote about in response to the three free text questions.

Categories	
Stress/worry	Emotional pressure or worry and stresses caused or relieved by the personal budget including responsibility of managing the budget. Stress and worry alleviated by the support provided through a personal budget.
Health	The impact that the personal health budget had on the person's physical or mental health. Including how the budget impacted on their recovery or reduced the impact of their condition on their life.
Independence	The impact of the personal health budget on the person's mobility, access to local community facilities and services. Remaining in their own home rather than in hospital or a care home.
Choice/control	The degree of choice and control the personal health budgets had allowed over treatment and support, and in other aspects of life.
Support/treatment	The nature, location, timing, and type of treatment or support available as a result of the personal health budget.
Quality of life	Life experiences affected by having a personal budget, including impact on emotional wellbeing, and ability to manage their health condition and on relationships with their family.
Home	The impact of the personal budget on the person's home life.
Funding/service level	The amount of money in the budget or service available as a result of having a budget.
Timeliness	Speed with which the personal budget was allocated and the time it took to establish and appropriate support package.
Process	The experience of getting and controlling a budget. In particular the paper work involved in applying for or accounting for a budget.
Personal health budget	The idea of personal health budget.
Equipment	The value of being able to acquire specific equipment or the desire to do so with a personal health budget. The impact of equipment on the person's life.
Employment	Issues associated with recruiting and managing staff who provide support.
Advice	Information, advice, guidance and support available to people taking control of a personal health budget. Including clear policy and procedure and details of service options. Information about how the process worked what was or was not permitted, information about available support options.

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



WHAT FACTORS ARE ASSOCIATED WITH POSITIVE OUTCOMES FOR PERSONAL HEALTH BUDGET HOLDERS?

Figure 9 previous shows how personal budget holders feel their personal health budget has affected (or not) 15 areas of their lives. In this section of the report we will ask four further questions:

1) Are there differences in the outcomes of personal health budgets depending on age, gender or current health status?
2) Are aspects of personal health budget usage (organisation administering the personal health budget, previous local authority support, length of time with personal health budget, type of personal health budget, knowledge of the cost of personal health budget, support in personal health budget planning, feeling that your views are included in the support plan) associated with positive outcomes?
3) Are personal health budget holders' perceptions of the processes involved in holding a personal health budget associated with positive outcomes?
4) Is what people have spent their personal health budget on associated with positive outcomes?

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

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

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

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

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

Table 1 opposite shows whether three personal factors (the personal health budget holder being 65 years old or older, female, or reporting themselves as in fair/bad/very bad health), the organisation funding the personal health budget (NHS, council, or both), and whether the personal health budget holder had been receiving social services support before the personal health budget or not, were associated with personal budget holders reporting a positive impact of their personal health budget on 14 areas of people's lives we asked about (the number of people reported a positive impact on paid work was too small for odds ratios to be calculated).

Table 1 shows firstly that people's age or gender were largely unrelated to any of the outcome indicators, with the exception that women were more than twice as likely as men to report their personal health budget having a positive impact on who and where they lived.

Table 1 also shows that people with poorer self-reported health were at least four times more likely to report a positive impact of personal health budgets than people with good self-reported health, on: quality of life, self-esteem, being treated with dignity, and relationships with family, friends and others paid to support the person.

There was little difference whether the budget was managed by the NHS or by the council, with only one association between the agency organising the personal health budget and perceived impact in all the areas we looked at, the only statistically significant association being that people with NHS-organised budgets were three times more likely to report a positive impact of their budget on arranging their support.

Finally, there was only one association between perceived impact and whether the person had been getting council support before their personal health budget: people who had been getting council support before their budget were less likely to report a positive impact of their budget on the degree of control they had over their life.

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 positive outcome: Personal factors and the main personal health budget organisation						
	65 years old or over	Female gender	Fair/ bad/ very bad health	NHS organising personal health budget	Council organising personal health budget	Both NHS & council organising personal health budget	Council support before personal health budget
Quality of life	1.48	2.02	5.26*	1.75	0.34	1.11	1.19
Self-esteem	1.24	1.30	5.00*	2.49	0.80	0.33	0.90
Relationships – paid	2.27	2.04	5.56*	1.36	0.46	1.12	1.93
Friends	0.81	1.67	8.33*	1.10	0.76	1.06	1.27
Relationships – family	1.61	1.32	9.09*	1.62	0.32	1.15	1.27
Volunteer – community	0.23	2.36	8.33	1.58	1.77	0.33	0.79
Paid work	n/c	n/c	n/c	n/c	n/c	n/c	n/c
Who and where you live	2.30	2.64*	1.37	1.62	0.38	1.00	2.16
Feeling safe	1.40	1.49	2.50	1.66	0.48	0.85	1.12
Arranging support	1.34	0.98	1.64	3.01*	0.33	0.49	0.40
Independence	0.78	1.63	0.98	1.18	0.41	1.87	0.75
Control over life	0.49	1.63	1.22	2.14	0.47	0.56	0.39*
Mental health	0.67	1.20	1.82	1.68	0.78	0.56	0.90
Physical health	0.80	1.67	1.35	1.38	0.66	0.85	0.62
Dignity	0.83	1.87	4.17*	1.27	0.52	1.14	0.72

n/c=Odds ratio not calculable

Table 2 opposite 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 14 outcome indicators.

The length of time people had held their personal health budget was not associated with any outcome indicator.

There were also very few associations between the type of personal budget people held and perceptions of positive impact. People with a direct payment paid to a broker were five times less likely to report a positive impact of their budget on their self-esteem, and people with a direct payment paid to family/friends were more than three times as likely to report a positive impact of their budget on where and who they live with.

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

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						
	Personal health budget held for >1 year	Direct payment paid to own account	Direct payment paid to broker	Direct payment paid to family or friend	Provider-managed Personal health budget	NHS/ council-managed personal health budget	Know support costs
Quality of life	1.61	0.34	0.62	1.66	n/c	n/c	1.61
Self-esteem	0.83	1.20	0.20*	1.11	1.09	n/c	1.11
Relationships – paid	1.70	0.60	1.43	1.41	2.54	1.17	1.20
Friends	1.09	0.72	1.15	1.12	0.99	4.32	0.97
Relationships – family	1.83	0.87	1.97	1.41	0.54	0.68	1.71
Volunteer – community	1.61	1.63	2.13	0.43	0.47	2.13	0.44
Paid work	n/c	n/c	n/c	n/c	n/c	n/c	n/c
Who and where you live	1.73	0.42	0.40	3.74*	1.71	0.50	0.95
Feeling safe	1.44	0.63	0.52	2.25	0.67	3.82	0.68
Arranging support	2.51	1.12	0.27	1.47	1.20	2.03	0.73
Independence	2.42	0.47	1.03	2.31	0.55	n/c	0.91
Control over life	0.69	1.22	0.91	0.83	0.28	n/c	1.29
Mental health	0.52	1.38	0.86	0.54	0.74	n/c	2.05
Physical health	0.64	1.53	0.83	0.53	0.52	n/c	1.79
Dignity	1.81	0.77	0.88	2.62	0.39	1.59	0.65

n/c=Odds ratio not calculable

Table 3 opposite shows potential associations between various aspects of the personal health budget planning process (who helps the person to plan) and positive outcomes for 14 outcome indicators.

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; people could record getting help to plan from more than one source):

- People who had help to plan from family/friends were almost seven times more likely to report their budget having a positive impact on their quality of life.
- Getting help to plan from someone in the council or from a service provider was not associated with any outcome indicator to a statistically significant level.
- People who got help to plan from someone in the NHS were almost five times more likely to report a positive impact of their budget on their independence, and more than three times more likely to report a positive impact of their budget on them feeling safe.
- People who got help from someone independent of the council or NHS were five times less likely to report their budget having a positive impact on their independence.
- People who planned their support themselves without any help were at least four times less likely to report a positive impact of their budget on their self-esteem, their relationships with others paid to support them and relationships with family, feeling safe, having control over their life, physical health, and being supported with dignity.

"People who had help to plan from family/friends were almost seven times more likely to report their budget having a positive impact on their quality of life."

TABLE 3: Aspects of support planning: Associations with positive outcomes for personal health budget holders

Outcome	Factors potentially associated with outcome: Support in the personal health budget planning process					
	Family/ friends help to plan	Council helps to plan	Plan without help	NHS helps to plan	Independent person helps me to plan	Provider helps me to plan
Quality of life	6.80*	0.56	0.27	0.68	0.82	n/c
Self-esteem	1.39	1.32	0.21*	1.32	1.12	1.26
Relationships – paid	1.88	2.07	0.17*	1.49	0.57	4.91
Friends	1.38	1.35	0.42	1.55	0.52	1.14
Relationships – family	1.33	1.72	0.23*	1.10	0.76	0.93
Volunteer – community	3.06	2.29	0.67	0.51	0.67	n/c
Paid work	n/c	n/c	n/c	n/c	n/c	n/c
Who and where you live	1.27	0.80	0.26	0.84	1.03	2.67
Feeling safe	1.27	0.87	0.25*	3.44*	0.40	0.67
Arranging support	0.90	0.87	0.55	2.32	0.62	n/c
Indepen-dence	1.88	0.48	0.37	4.87*	0.16*	4.52
Control over life	1.21	1.40	0.28*	1.77	0.75	1.09
Mental health	0.88	1.64	0.53	2.38	1.22	2.75
Physical health	0.68	1.39	0.09*	1.70	0.79	1.71
Dignity	1.12	3.91	0.19*	1.64	0.51	0.77

n/c=Odds ratio not calculable

Table 4 opposite shows potential associations between people's perceptions of whether their views were fully included at three points in the personal health budget planning process and positive outcomes for 14 outcome indicators.

Almost all respondents to the POET survey reported that their views were fully included when their needs were being assessed and when the support plan was being written, meaning that there was little variation in the data for odds ratios to be calculated. Nevertheless, people who felt their views were fully included when their support needs were being assessed were at least 10 times more likely to report a positive impact of their budget on their mental health and their independence, and 20 times more likely to report a positive impact on their quality of life. In addition, people who felt that their views were fully included when their support plan was being written were again almost 20 times as likely to report a positive impact of their budget on their quality of life.

Although still a majority, fewer people reported that their views were fully included when the amount of their personal budget was being set, given more variation for odds ratio calculations. If people felt their views were fully included when the budget was being set, they were more likely to report a positive impact of their budget on 13 areas of their life:

- People were around four times more likely to report a positive impact on their relationships with others paid to support them, who and where they lived and control over their life.
- People were between five and 10 times more likely to report a positive impact on their quality of life, self-esteem, relationships with friendships, feeling safe, independence and physical health.
- People were at least 10 times more likely to report a positive impact on their relationship with family and their mental health.
- People were at least 20 times more likely to report a positive impact on being supported with dignity.

"People who felt their views were fully included at assessment were 20 times more likely to report a positive impact on quality of life."

TABLE 4: Views included in the planning process: Associations with positive outcomes for personal health budget holders

Outcome	Factors potentially associated with outcome: Views included in the personal health budget planning process		
	Views included when needs assessed	Views included when budget amount was set	Views include when support plan written
Quality of life	23.18*	5.69*	19.5*
Self-esteem	8.64	8.51*	n/c
Relationships – paid	n/c	3.93*	n/c
Friends	n/c	6.29*	n/c
Relationships – family	n/c	11.39*	n/c
Volunteer – community	n/c	2.67	n/c
Paid work	n/c	n/c	n/c
Who and where you live	3.08	4.32*	n/c
Feeling safe	2.35	8.96*	n/c
Arranging support	3.02	4.81*	n/c
Independence	11.70*	6.80*	8.88
Control over life	4.32	5.42*	6.27
Mental health	10.00*	11.18*	n/c
Physical health	7.31	8.85*	n/c
Dignity	1.67	23.13*	n/c

n/c=Odds ratio not calculable

Table 5 opposite shows potential associations between whether the organisation funding the person's personal health budget had made nine aspects of the personal health process easy or not and 14 of the 15 outcome indicators we asked about.

As Table 5 shows, making almost all aspects of the personal health budget process easier was associated with indicators of positive outcomes:

- Making it easy to get information and advice was associated with positive impacts of the budget on quality of life, arranging support, independence, mental health and physical health.
- Making it easy to agree the amount of the budget was associated with a positive impact of the budget on the person being supported with dignity.
- Making it easy to understand how the budget could be spent was associated with a positive impact of the budget on the person being able to arrange their support.
- Making it easy to plan the support and making it easy to choose support were associated with positive impacts of the budget on the person's independence and the person being supported with dignity.
- Making it easy to get the support the person wanted was associated with positive outcomes for 10 of the 14 outcome indicators analysed.
- Making it easy to change the person's support was associated with positive impacts of the budget on arranging support, independence and the person having control over their own life.
- Making it easy for the person to manage their support day to day was associated with positive impacts of the budget on arranging support and the person having control over their own life.
- Finally, making it easy to account for how the budget was spent was associated with a positive impact of the budget on the person having control over their own life.

"Making it easy to get information and advice was associated with positive impacts of the budget on quality of life"

TABLE 5: Experience of the personal health budget process: Associations with positive outcomes for personal health budget holders

Outcome	Factors potentially associated with outcome: How easy are the following aspects of the personal health budget process								
	Get info & advice	Agree amount of personal health budget	How to spend personal health budget	Plan support	Choose support	Get sup-port you want	Change your support	Manage support day to day	Account-ing for spend
Quality of life	4.35*	2.27	2.12	1.70	3.04	4.08*	2.70	3.55	1.95
Self-esteem	2.13	1.92	2.37	2.22	2.24	3.58*	2.67	2.26	1.19
Relationships – paid	1.64	1.79	0.77	1.76	2.86	4.63*	1.56	1.81	0.77
Friends	2.27	1.16	1.40	0.93	1.40	2.04	1.33	1.67	0.54
Relationships – family	1.85	1.39	1.22	0.83	1.12	2.60	1.29	1.42	0.48
Volunteer – community	0.39	0.45	1.31	0.70	0.63	0.44	1.79	0.33	1.00
Paid work	n/c	n/c	n/c	n/c	n/c	n/c	n/c	n/c	n/c
Who and where you live	3.03	1.25	3.07	1.72	1.56	3.52*	1.57	2.00	1.64
Feeling safe	1.11	1.72	1.47	2.28	2.07	3.47*	1.79	1.15	1.65
Arranging support	3.45*	2.08	3.72*	2.90	2.08	7.41*	3.65*	5.29*	2.33
Independence	3.23*	2.50	1.64	3.44*	3.45*	6.76*	4.10*	2.86	1.72
Control over life	2.50	1.64	1.62	2.21	2.06	3.76*	7.04*	4.52*	5.21*
Mental health	2.78*	0.99	0.86	0.67	1.06	1.75	1.90	1.87	0.80
Physical health	4.35*	1.41	1.12	1.40	2.26	3.24*	2.56	2.96	1.63
Dignity	1.92	3.03*	1.31	4.08*	3.06*	6.80*	2.28	2.25	0.97

Table 6 opposite shows potential associations between what the budget was spent on and 14 of the 15 outcome indicators we asked about.

People who used their budget for care and support services were more likely to report their personal health budget having a positive impact on their friendships, on feeling safe, and on their mental health. People who used their budget for community and leisure activities were also more likely to report their budget having a positive impact on their mental health.

People who used their budget for a personal assistant were less likely to report a positive impact of their budget on arranging their support, and using the budget for equipment was not associated with any outcome indicators.

TABLE 6: What the budget is spent on: Associations with positive outcomes for personal health budget holders

Outcome	Factors potentially associated with outcome: What the budget is spent on			
	Care and support	Community and leisure	Personal assistant	Equipment
Quality of life	2.71	1.37	1.40	0.70
Self-esteem	1.87	1.18	1.44	0.67
Relationships – paid	2.25	1.24	1.64	0.56
Friends	3.22*	1.36	2.22	0.68
Relationships – family	2.20	1.13	1.73	0.53
Volunteer – community	0.60	0.31	1.61	2.90
Paid work	n/c	n/c	n/c	n/c
Who and where you live	1.17	1.20	1.50	2.10
Feeling safe	2.41*	1.19	1.46	0.96
Arranging support	2.52	2.31	0.27*	0.98
Independence	1.79	1.57	0.49	1.35
Control over life	1.93	0.88	0.67	0.67
Mental health	3.02*	2.80*	0.87	0.98
Physical health	2.06	1.80	0.62	1.52
Dignity	1.89	1.53	1.09	0.95

n/c=Odds ratio not calculable

8 MAIN FINDINGS: CARERS

Most respondents were White (93.3%) and women (63.1%), with the vast majority aged 45 or over (85.4%).

Less than a fifth of carers (18.8%) reported themselves to have a disability, most commonly a physical disability (11.9%).

Carers reported their general health somewhere between that of the general population in England and that of the people they were supporting. More than half of carers (54%) reported their health as good or very good, a small number of carers (7%) reported their health as bad or very bad.

Carers were most commonly caring for a partner/spouse (48%), followed by a grown-up son or daughter (30%), with a small proportion of carers supporting a parent (5%) other relative (11%), or a friend/neighbour (6%).

More than three quarters of carers (82.2%) were living in the same house as the person they were caring for, and a majority of carers (56.4%) were spending more than 50 hours per week caring.

In terms of carers' views being included in the personal health budget process, a substantial majority said their views had been taken into account when the needs of the person they care for were assessed (89.1%) and when the person's support plan was written (80.2%). The majority said their views had been taken into account when their needs as a carer were assessed (69.3%) and when the budget was agreed (72.3%).

Nearly two thirds of carers (64.4%) knew the amount of the personal health budget held by the person they were supporting.

IN TERMS OF THE IMPACT ON THE CARER OF THE PERSONAL HEALTH BUDGET HELD BY THE PERSON THEY WERE SUPPORTING:

More than 80% of carers who said that the question was relevant to them, reported a positive impact of personal health budgets on: the support you need to continue caring (90.6%), carers' quality of life (86.5%), and the quality of life of the person receiving budget (89.2%).

More than 70% of carers who said that the question was relevant to them, reported a positive impact of personal health budgets on: their day-to-day stress (79.8%), and the choice and control they had over the important things in their life (79.8%).

Just over half of carers who said that the question was relevant to them, reported a positive impact of personal health budgets on: being able to do paid work/ volunteering (56.9%), their relationship with the person they care for (55.4%), and their relationships with other family and friends (52.3%).

Less than 5% of carers reported any areas of their lives getting worse as a result of personal health budgets.

The majority said their views had been taken into account when their needs as a carer were assessed

9 DETAILED FINDINGS: CARERS

Who responded to the POET survey?

As mentioned earlier in this report, a total of 101 carers completed the POET survey and gave their agreement for the information to be used. As people could choose not to complete particular questions within the survey, percentages are of the total responding to that particular question. In some areas respondents were asked to indicate if a particular question was not relevant to them.

Equalities monitoring information for carers shows:

- Most respondents (63.2%) were women.
- In terms of age, 12.5% of carers were aged 16-44 years, 53.1% were aged 45-64 years, and 33.4% were aged 65 years or over.
- Most respondents were White (93.3%).
- Most respondents were Christian (64.4%), with 24.1% reporting themselves to have no religion.
- Most respondents reported themselves to be heterosexual/straight (96.5%).
- A significant minority of carers (18.8%) reported themselves to have a disability, most commonly a physical disability (11.9%).

As we did with personal health budget holders, we asked the same question used in the 2011 census concerning people's self-rated general health in general to carers. As Figure 12 shows, the carers responding to the POET reported their health somewhere between that of the general population in England and that of the people they were supporting. More than half of carers (54%) reported their health as good or very good, compared to less than a quarter (20.8%) of personal health budget holders and over three-quarters (81.4%) of the general population. The number of carers that reported their health as bad or very bad was 7%, compared to more than a third (36.9%) of personal health budget holders and 5.4% of the general population.

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

WHAT ARE THE CIRCUMSTANCES OF CARERS?

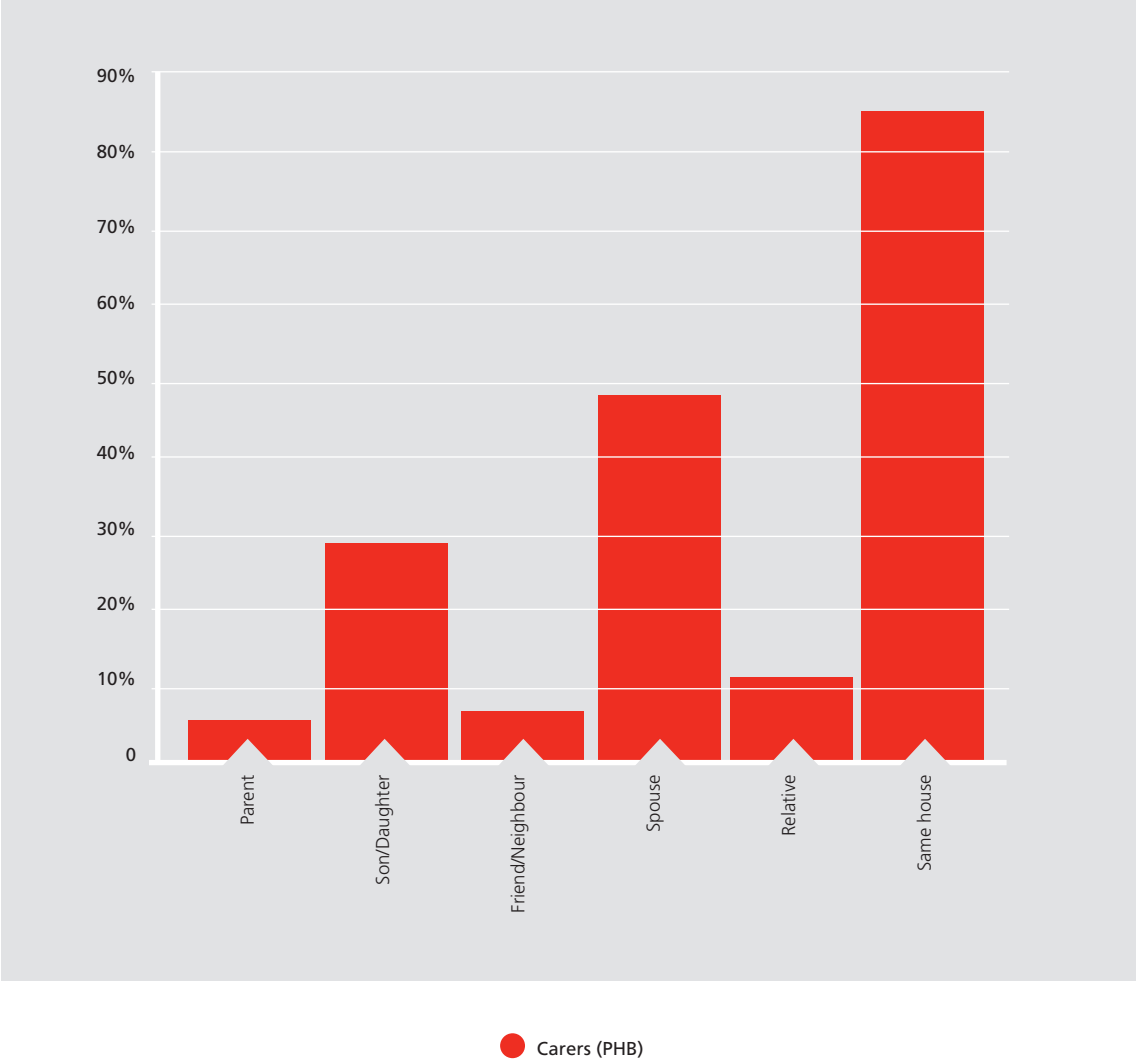
The POET survey asked carers a number of questions about their current circumstances regarding their caring role.

Figure 13 shows who carers in the POET survey were offering care and support to. Carers were most commonly caring for a partner/spouse (48%), followed by a grown-up son or daughter (29.6%) then an older family member (26.5%), with a small proportion of carers supporting someone else e.g. a friend or neighbour (6.1%), parent (5.1%) other relative (11.2%).

Figure 13 also shows that well over three quarters of carers (84.7%) were living in the same house as the person they were caring 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.

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

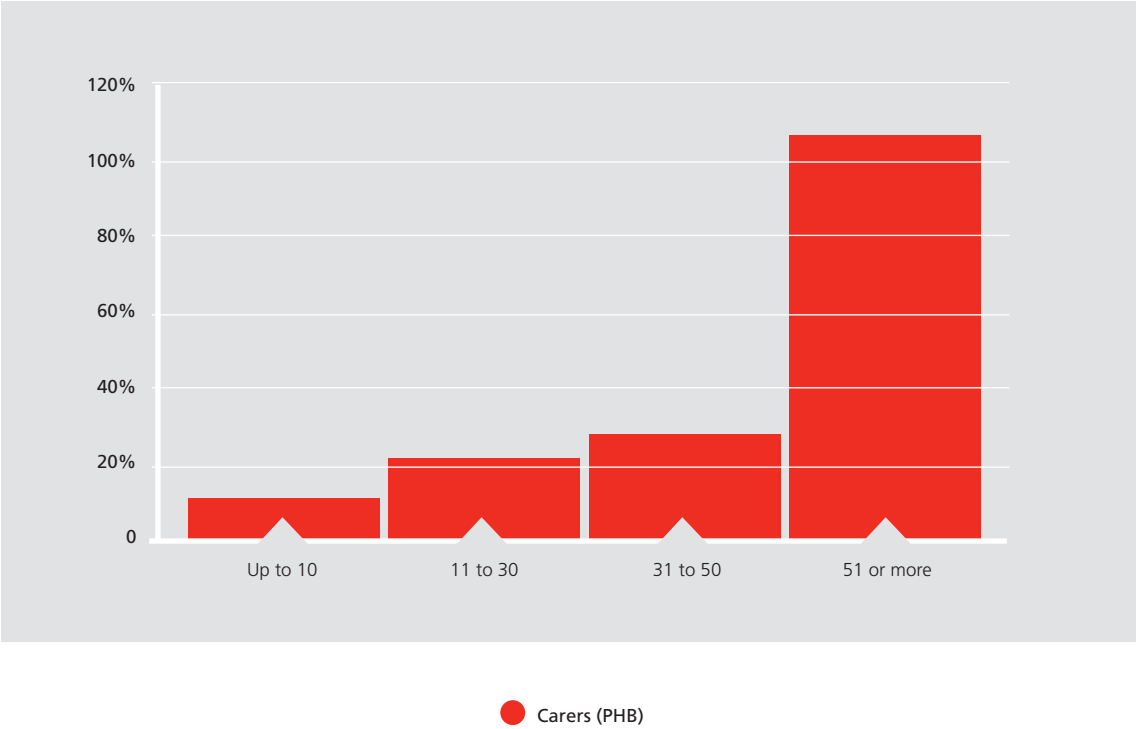


Carers who were living in the same house as the person they were caring for[22] and carers who were caring for a son/daughter on average reported spending more hours caring[23].

22 *U=441.5, n=101, p=0.002*

23 *U=752.5, n=101, p=0.015*

FIGURE 14: Estimated hours per week spent caring



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

This information shows:

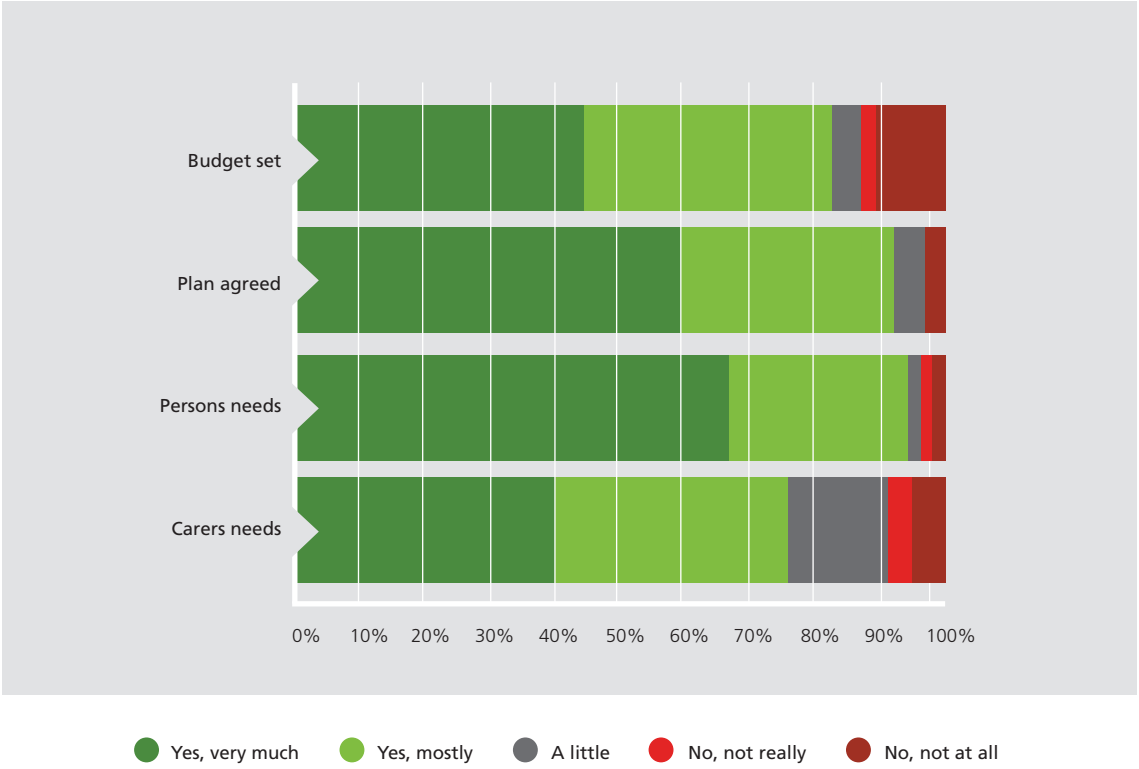
- Of the personal health budget holders being supported by carers, 35.1% had had their personal budget for less than a year, 43.3% had had their personal budget between one and three years, and 21.6% had had their personal budget for over three years.
- More than two thirds (71.6%) of the people being supported by carers had received paid care or support before their personal health budget.
- More than three quarters of carers (79.8%) knew the amount of the personal health budget held by the person they were supporting.

Carers' experience of the personal health budget process

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

Figure 15 below shows at least two thirds of carers (72.9%) felt that their views were included mostly or very much in all aspects of the process we asked about. Of the four areas we asked about carers were most likely to say their views had not been included when the budget was set (12.4%).

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



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

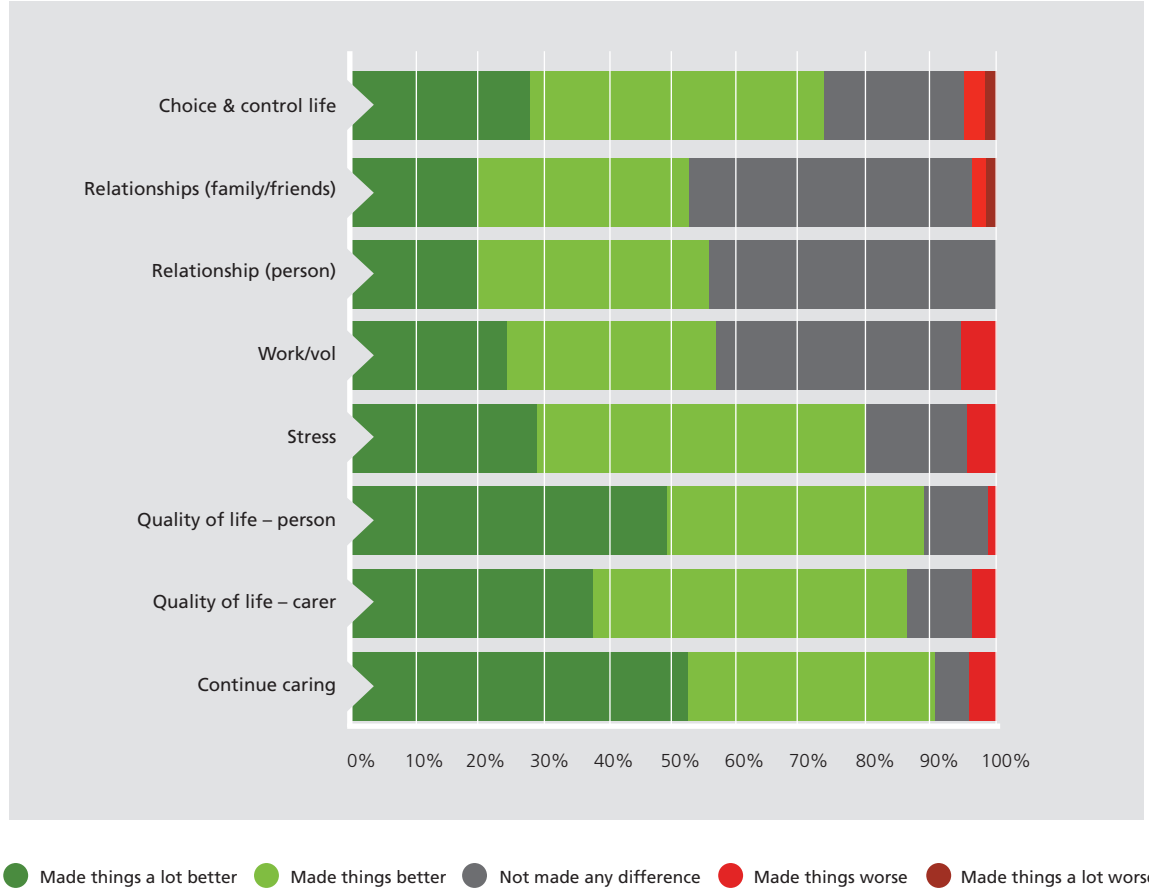
More than three quarters of carers said that the person they care for having a personal health budget had made things better or a lot better in half of the eight aspects we asked about; day-to-day stress (79.8%), continue caring (90.6%), quality of life for the carer (86.45%), quality of life for the person being cared for (89.2%).

More than two thirds of carers said that the person they care for having a personal health budget had made things better or a lot better in terms of the choice and control the carer has in life (73.5%).

More than half of carers said that the person they care for having a personal health budget had made things better or a lot better in three of the eight aspects we asked about; work or volunteering (56.9%); relationship with the person being cared for (55.4%), relationships with family and friends (52.3%).

Less than 6% of carers reported any areas of their lives getting worse as a result of personal health budgets.

FIGURE 16: Outcomes for carers



WHAT WORKED WELL, WHAT DIDN'T AND WHAT WOULD CARERS CHANGE?

As with personal health budget holders, carers were asked to comment about their experience of having a personal health budget. We asked carers what worked well, what didn't work well and what specific changes they would make. Nearly two thirds of carers commented on what had worked well (64.3%), more than a third commented on what had not worked well (39.6%), and less than half made a comments suggesting changes (45.5%).

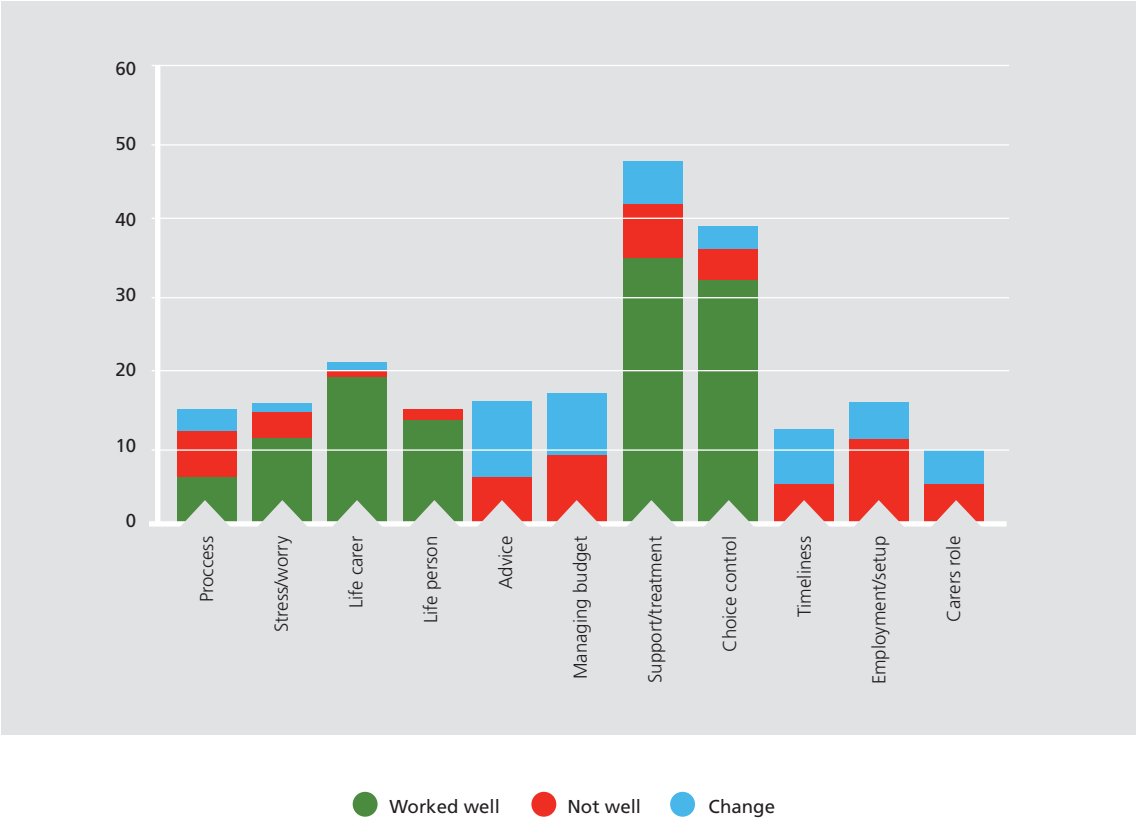
The length of response varied from a couple of words to several sentences, with most people providing just a single sentence. Responses tended to illustrate peoples experience of the process of taking control of a personal health budget or the impact the personal budget had on their life.

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

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

Process	The experience of getting and controlling control of a budget. In particular paper work involved in applying for or accounting for a budget.
Stress/worry	Emotional pressure or worry and stresses caused or relieved by the personal budget Including responsibility of managing the budget. Stress and worry alleviated by the support provided through a personal budget.
Life for carer	The impact of the personal health budget for the person they care for on the carer's life.
Life for the person	The impact of personal budgets on the life of the person they cared for.
Advice	The information, advice and guidance and support available to people taking control of a personal health budget. Including clear policy and procedure and details of service options.
Managing budget	The experience of managing a personal health budget.
Support/ treatment	The quality, nature, range, impact, and availability of support and treatment as a result of having a personal health budget including the degree of flexibility and choice.
Choice/control	The degree of choice and control the personal health budgets had allowed over treatment and support, and in other aspects of life.
Timeliness	The length of time taken to get the personal health budget up and running.
Employment/ setup	The responsibility and difficulty of recruiting managing and employing paid staff.
Carers role	The impact of having a personal health budget on the role of the carer. Including the introduction of other paid carers and the demands of organising support and managing a personal health budget.

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



WHAT FACTORS ARE ASSOCIATED WITH POSITIVE OUTCOMES FOR CARERS?

Figure 16 previous shows how family carers feel the personal health budget for the person they are supporting has affected (or not) eight areas of their lives. In this section of the report we will ask three further questions:

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

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

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

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

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

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

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

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

Table 7 opposite shows whether three personal factors (the family carer being less than 65 years old, female, or reporting themselves as in very good/good health), and the person the family carer was supporting (son/daughter and spouse/partner, where there were sufficient numbers for statistical analysis), were associated with family carers reporting a positive impact of the person's personal health budget on eight areas of carers' lives.

TABLE 7: Personal factors and who the carer is caring for: Associations with positive outcomes for family carers

Outcome	Factors potentially associated with positive outcomes for family carers: Personal factors and relationship of the carer to the personal budget holder				
	Carer 65 years old or over	Carer female gender	Carer very good/ good health	Caring for son/ daughter	Caring for spouse/ partner
Choice and control-carer life	1.38	0.76	0.42	2.58	2.60
Relationships family/friends	0.60	0.81	0.62	4.20*	0.70
Relationship with personal health budget holder	0.74	0.52	0.50	1.69	1.76
Work/ voluntary activity	0.36	1.80	1.03	2.28	0.90
Stress/worry	0.77	0.50	0.35	1.32	2.35
Quality of life personal health budget holder	0.70	0.42	0.51	4.58	2.28
Quality of life carer	1.17	0.83	0.48	0.92	2.31
Continuing caring	1.88	0.88	0.13	n/c	1.87

n/c=Odds ratio not calculable

Carer age, gender or self-assessed health was not associated with any outcomes for family carers. Carers caring for a son/daughter were more likely to report a positive impact of their son/daughter's budget on their relationships with other family and friends, but there were no other associations.

Table 8 opposite shows potential associations between various aspects of the caring situation for the family carer and aspects of the personal health budget (having held a budget for more than a year, whether the carer knows the amount of the budget) and positive outcomes for carers for eight outcome indicators.

Table 8 shows that whether carers whether caring for more than 50 hours per week or not was not associated with any outcome indicators for family carers. Carers living in the same house as the personal budget holder were more likely to report a positive impact of the person's budget on their levels of stress and worry as carers, on the quality of life of the carer and on the carer's capacity to continue caring.

Table 8 also shows that whether the person had been getting service support was not associated with any outcome indicators for family carers. If the person had been getting a personal health budget for longer than one year, carers were more likely to report a positive impact of the person's budget on carers' levels of stress and worry. Finally, if carers knew the amount of the person's budget they were more likely to report a positive impact of the person's budget on the carers' capacity to continue caring.

Table 9 following shows potential associations between carers' perceptions of whether their views were fully included at four points in the personal health budget planning process and positive outcomes for carers across eight outcome indicators.

The small number of family carers reporting that their views were not fully included in various parts of the personal health budget process means that statistically significant odds ratios are unlikely. However, carers who reported their views were fully included when the needs of the personal health budget holder were being assessed were 10 times more likely to report a positive impact of the person's budget on carers' levels of stress and worry.

Carers who reported that their views were fully included when their needs as carers were being assessed were at least three times more likely to report a positive impact of the person's budget on the carers' relationships with other family and friends, on work and voluntary activity, on carers' levels of stress and worry, and on carers' quality of life.

TABLE 8: Aspects of caring and the personal health budget: Associations with positive outcomes for carers

Outcome	Factors potentially associated with outcome: Aspects of caring and the personal health budget				
	Caring for 50+ hrs per week	Carer in same house as personal health budget holder	Person had support before personal health budget	Personal health budget held for >1 year	Know amount of personal health budget
Choice & control – carer life	0.92	1.75	1.17	1.26	2.84
Relationships family/friends	1.20	2.10	1.77	1.67	2.13
Relationship with personal health budget holder	1.06	1.29	1.87	2.28	1.69
Work/ voluntary activity	1.22	2.18	2.53	2.46	2.89
Stress/worry	1.97	3.87*	2.65	3.47*	1.99
Quality of life personal health budget holder	1.89	1.48	1.74	3.11	0.65
Quality of life carer	3.79	4.56*	2.24	2.38	1.97
Continuing caring	2.83	5.00*	1.88	1.57	4.47*

n/c=Odds ratio not calculable

TABLE 9: Views included in the planning process: Associations with positive outcomes for family carers

Outcome	Factors potentially associated with outcome: Views included in the personal health budget planning process			
	Views included when personal health budget holder needs assessed	Views included when carer needs assessed	Views included when budget amount was set	Views included when support plan written
Choice and control-carer life	2.04	2.36	3.73	0.70
Relationships family/ friends	6.11	3.80*	3.13	1.53
Relationship with personal health budget holder	1.27	2.22	1.25	0.96
Work/voluntary activity	2.45	6.04*	3.32	6.67
Stress/worry	10.14*	4.54*	2.27	3.48
Quality of life personal health budget holder	1.90	0.86	1.27	n/c
Quality of life carer	4.33	7.11*	2.50	1.32
Continuing caring	2.70	2.57	0.88	n/c

n/c=Odds ratio not calculable

10 NEXT STEPS

The local data from the POET surveys is currently being shared with participating councils and CCGs and they are being encouraged to use this data to develop action plans to support the introduction of personal health budgets.

The data from this national report will be used by NHS England and TLAP to provide support and guidance to assist sites in the roll out of personal health budgets.

Less than 5% of carers reported any areas of their lives getting worse as a result of personal health budgets.

Think Local Act Personal

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

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