



THIRD NATIONAL PERSONAL BUDGET SURVEY

Experiences of personal budget holders and
carers across adult social care and health

 **POET**™
Personal Outcomes Evaluation Tool



Acknowledgements

This work would not have been possible without the commitment, enthusiasm and contributions of many people. We are particularly indebted to everyone who has helped to devise, develop and implement POET as well as the staff from the each of the local authorities using POET and the individuals too numerous to mention who took the time to promote and encourage people to complete the survey. We of course would also like to extend our since thanks to the personal budget holders and carers who took the time to complete the surveys and share their experiences.

Finally we would also like to thank all the NHS and local government organisations who have taken part in the Third National Personal Budget Survey and for their ongoing commitment to use the findings to further improve the delivery of personal budgets for people locally.

Any errors of omission or interpretation are wholly the responsibility of the authors.

About this paper

This paper has been funded by a Department of Health grant and has been researched and written by In Control and Lancaster University and published by Think Local Act Personal (TLAP).

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 via personal budgets. It is therefore vital to TLAP 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 is linked 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 budgets, we will also be able to explore the experience of family carers to see what works best for them.

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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 budgets can be found at: www.thinklocalactpersonal.org.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.

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

NOTE: When referring to personal budgets in this paper we are referring to budgets across social care and health.

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FOREWORD



I warmly welcome this third national personal budget survey and advise all Directors of Adult Social Services and their staff to study its findings carefully. We must strive to improve the outcomes people experience as a result of using personal budgets, not just focus on increasing the numbers. We should always be asking, “are people getting better lives?” and “is the experience simpler and more flexible?”

Over 4000 people and carers shared their experiences for this report – the largest ever number – offering valuable insight into what is working well and not so well. The findings suggest people continue to experience positive effects of using personal budgets and improvements to feelings of dignity, independence and quality of life.

It is clear though there remains significant room for delivery improvement. People report they are frustrated by process. People with different needs and carers in different circumstances are still not universally benefitting from personal budgets and their experiences still depend on where they live.

This report gives strong clues on how to achieve improvements by showing the practice and process conditions that lead to better outcomes. There is no good reason not to implement the best practice. TLAP has produced and commissioned a wide range of practical resources that councils can use to help with this.

I would like to thank In Control for developing and supporting councils to use the Personal Outcome and Evaluation

Tool (POET) survey tool upon which it is based. Personal budgets are a core part of the Care Act and thus the future of social care. It is vital councils gain feedback directly from people and carers, and in a way that allows them to compare local delivery with other councils.

Earlier this year I wrote to all Directors of Adult Services encouraging use of POET to ensure proper self-awareness about local delivery. The Department of Health provided support to make this possible and a number of ADASS regions are supporting their members with this. Last year 22 councils undertook the POET survey. This year, 43 councils completed or have a start date for using POET and a further 33 have signed up or expressed interest. This increase is welcomed, but over the next year I would like to see all councils both becoming self-aware about local personal budgets delivery and using the practical materials available to drive forward improvements.

Norman Lamb MP

Minister of State for Care and Support

1 INTRODUCTION

Personal budgets are now a core part of social care and will be an increasingly significant part of the future of healthcare and education for many. We have moved on from their introduction in the Putting People First concordat in 2007 with an expectation that 30% of people would be using them by 2011 – to the Care Act requirement that all eligible people should hold one.

We have seen personal health budgets go from a three year pilot programme to the first stages of roll out in continuing healthcare. The Integrated Personal Commissioning Programme¹, announced by NHS Chief Executive Simon Stevens in September, aims to put joint health and social care personal budgets at the heart of integration, at the level of the individual. This was echoed in the King's Fund paper 'Commission on the Future of Health and Social Care in England'². Personal budgets are also prominent in the special educational needs and disability (SEND) reform programme³.

We are now moving on helpfully from questioning whether personal budgets have a part to play in public services to more useful questions about how they can offer maximum benefit to those using them within a changing context.

And yet, we are actually still in the relatively early days of the introduction of personal budgets and there is much learning and progress still to be made. As with any powerful innovation many factors can affect implementation and delivery can be uneven. All this means that it is vital that at both national and local levels we learn about what works best and apply the lessons.

1 www.england.nhs.uk/ourwork/commissioning/lipcl/

2 www.kingsfund.org.uk/projects/commission-future-health-and-social-care-england

3 www.gov.uk/government/uploads/system/uploads/attachment_data/file/342440/SEND_Code_of_Practice_approved_by_Parliament_29.07.14.pdf

Two continuing challenges confirmed by the data in this report are:

- 1) There remain big variations in delivery including across places and groups and in the ways people take and manage their personal budgets. Some places are offering much better process and outcomes than others. Where there is poor practice and process people are reasonably asking critical questions about personal budget delivery.
- 2) Personal budgets can significantly improve lives and we are getting increasingly clear about what leads to the best results but many councils are not self-aware on personal budgets. Most are still not systematically checking results directly with people using personal budgets and family carers or using the findings to action improvements. Use of best practice approaches is not common enough, with many councils not using learning from their peers.



Underneath these general challenges are more specific questions including:

- How can personal budgets be better accessed and make the best positive difference for groups of people who may currently be benefitting less?
- What are the practices and key process conditions that are linked to the best results and how can best approaches become more widespread?
- What are the implications of current use and impact of personal budgets for councils' responsibilities for commissioning and provision of information and advice?

The government has helpfully shifted its focus from a simple numbers target, to concern about outcomes and experiences. But it is still only numbers that are formally collected in performance returns. We are encouraged that this year a substantial number of councils have undertaken or made a commitment to use POET to survey people's experiences and the impact on their lives – about half of English councils. However, this leaves half of councils not systematically checking results with people in a way that allows them to compare impact with other councils (although some may be using local surveys – this information is not centrally collected). Without this kind of information there is a real risk that at the least councils lack awareness and at worst poor decisions are being made about delivery of a core element of public policy.

How do the current findings help?

In general the findings on outcomes from personal budgets continue to be encouraging in many areas of life and support. Overall, more than three quarters of personal budget holders reported their budget having a positive impact on five of the 15 areas we asked about: dignity (82%); independence (78.9%); arranging support (79.9%); paid relationships (75.9%) and quality of life (81.4%). In addition at least two thirds of personal budget holders reported their budget having a positive impact on a further six of the 15 areas of life we asked about: mental health (65.5%); control over life (70.6%); feeling safe (72.8%); family relationships (74.6%); paid relationships (67.8%), and self-esteem (73.2%). Although there were some differences across groups, in this survey at least the results do not support the position that personal budgets are not working for older people in important life areas.

In respect of process, two issues are confirmed as significant. Firstly there is still consistent reporting by personal budget holders and carers that strongly suggests process needs to improve in most places and in many respects. This shows us that

organisational arrangements and system and practice cultures are proving hard to change in many places. Policy and practice guidance, improvement support and peer challenge clearly need to prioritise attention to these issues. TLAP is playing its part in this via commissioning practice guidance in several relevant areas.

Secondly, although care should be taken in interpretation, and findings are sometimes complex or difficult to interpret, there appear to be some strong correlations between process conditions and outcomes, with some councils managing to deliver better process and outcomes.

Consistent with previous surveys, people report significantly better outcomes if they also report that the council makes the process easy, and they feel fully included in budget setting and support planning. In terms of use of budgets there were better reported outcomes when people spent their budget on community or leisure activities and personal assistants, rather than 'traditional services'. Some of these apparently important process conditions may not require extra resources, rather different behaviours. Given the severe resource pressures faced by councils, councils should clearly pay attention to these issues and learn from the best examples.

2 BACKGROUND

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. It is also 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 councils, clinical commissioning groups (CCGs) and partner agencies need to establish if they are to maximise the efficiency and effectiveness of personal budgets. POET provides the opportunity for national and 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 budgets, and to inform action planning for improvement.

Prior to this report, two national reports (2011 and 2013) have been published by TLAP looking at people's experiences in adult social care, detailing the impact of personal budgets on more than 5,000 people⁴. A separate paper has also recently been published looking specifically at personal health budgets⁵ (the findings are also included within this paper).

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 (EHC) plan; the initial findings in this area were published

⁴ 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*

⁵ See www.thinklocalactpersonal.org.uk/coordinatedcare

in July 2014⁶. In total, more than 8,000 people across health, adult social care, and children's services have shared their experiences to date using POET.

This latest report includes data from more than 4,000 people – 2,679 personal budget holders and 1,328 carers of people in receipt of a personal budget. These data are collated from 26 councils and 20 NHS organisations, and build on our previous surveys and reports.

The POET survey gathered views and experiences of personal budget holders and their (mainly family) carers separately. The tools were designed to measure how well organisations are implementing personal budgets and to what effect. Specific questions investigate people's experience of the 'personal budget process' and their report of the impact (or not) of the personal 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 support, 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?

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 process⁷.

6 Hatton C & Waters J (2014) *Measuring the outcomes of EHC plans and personal budgets, In Control*

7 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.*

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.

It is important to bear in mind that the POET personal budget survey does not represent a nationally representative sample, and because of this overall statistics concerning outcomes must be treated with caution.



3 RESEARCH ETHICS

Because the POET surveys were designed for people to evaluate their experiences of existing personal budgets, the surveys are service evaluation rather than research according to guidance from the National Research Ethics Service⁸, and therefore did not require approval from the Research Ethics Committee.

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

All between-group differences and associations were conducted using the appropriate non-parametric test,

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

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 budget holders and carers.

⁸ National Research Ethics Service (2013). *Defining research*. London: Health Research Authority. www.hra.nhs.uk/documents/2013/09/defining-research.pdf

4 KEY FINDINGS

The impact of personal budgets on people who need support and their family carers was broadly positive for all groups involved in the survey.

At least two thirds of respondents said their personal budget had made things better or a lot better in 11 of the 15 areas of life we asked about:

- Dignity in support (82%)
- Independence (78.9%)
- Arranging support (79.9%)
- Relationships with people paid to support them (75.9%)
- Quality of life (81.4%)
- Mental health (66%)
- Control over life (70.6%)
- Feeling safe (72.8%)
- Family relationships (74.6%)
- Paid relationships (67.8%)
- Self-esteem (73.2%)

Fewer than 5% of people reported their personal budget having a negative impact on any of the 15 areas we asked about.

There were no differences between social care groups in the reported positive impact of personal budgets on eight of the 15 areas we asked about.

More than two thirds of carers said that as a result of the person they care for having a personal budget things had got better or a lot better in three of the eight aspects we asked about: continue caring (78.6%); quality of life for the person being cared for (79.6%); and quality of life for the carer (71.3%).

Personal factors such as gender, ethnicity, age or social care group were extremely rarely associated with outcome indicators.

MOST RESPONDENTS SAID THEIR VIEWS WERE INCLUDED

The majority of personal budget holders reported their views had been included when their needs were assessed (82%) and when their plan was developed (76.9%); a less substantial majority reported their views had been included when their budget was set (65.1%).

More than two thirds of carers (68.8%) felt that their views were included mostly or very much, in all aspects of the process we asked about.

A SIGNIFICANT NUMBER OF PEOPLE FOUND THE PROCESS DIFFICULT

Around a quarter of personal budget holders said that aspects of the process were difficult for them in three of nine areas we asked about: making changes to support (28.4%); information and advice (24.1%); and understanding restrictions placed on the use of the personal budget (23.6%).

A significant minority of people also found other aspects of the personal budget process had been made difficult: agreeing the budget (22.9%); getting support (21.2%); choosing support (19.5%); and planning support (19.5%).

People with learning disabilities and people with mental health difficulties were more likely to report that the council made things difficult. Older people were more likely to report the council making things neither easy nor difficult.

GOOD PERSONAL BUDGET PROCESS WAS REGULARLY ASSOCIATED WITH POSITIVE OUTCOMES

For most types of personal budget – direct payment, council managed, or individual service fund – there were relatively few associations with outcomes.

People who felt their views were fully included when their needs were being assessed were more likely to report positive impacts of their budget on 14 of the 15 outcome indicators.

People who felt their views were fully included when the amount of the budget was set and people who felt their views were fully included when their support plan was written, were more likely to report positive impacts of their budget on all 15 outcome indicators.

Better outcomes in quality of life and self-esteem were reported by people who had held their budget for more than a year, and a better outcome in where and who the person lived with was reported by people who had held their budget for more than three years.

KNOWING THE AMOUNT OF MONEY AND GOOD PLANNING

Carers who could report the amount of the person's budget were more likely to report positive impacts of the budget across seven of the eight outcome indicators. Personal budget holders who could report the amount of their personal budget were more likely to report positive impacts of their budget on their quality of life, arranging their support, being as independent as they wanted to be and their mental health.

Specific sources of support to plan were extremely rarely associated with outcomes, but people who planned their support themselves without any help were less likely to report positive impacts of their budget on 13 out of the 15 outcome indicators.

A USER FRIENDLY PROCESS

People who reported overall that the budget funder made the personal budget process easy were more likely to report positive impacts of their budget across all 15 outcome indicators.

PERSONAL, COMMUNITY-BASED SUPPORT

People using their budgets on care and support services were less likely to report positive impacts of their budgets on their quality of life, their self-esteem, their relationships with people paid to

support them, the extent of control over their lives, their mental health and being supported with dignity. While people using their budgets on community and leisure activities were more likely to report positive impacts of their budgets on their quality of life, their self-esteem, and their relationships with friends, family and people paid to support them, the extent of control over their lives and their mental health.

People using their budgets on personal assistants were more likely to report positive impacts of their budgets on 13 of the 15 outcome indicators.



People reporting that the process was easy were more likely to report positive impacts of their budget across all areas

5 MAKING USE OF THE FINDINGS

A survey of people's views and reported experiences such as that provided by POET can't answer all the questions councils, health organisations and their partners might want to ask about what they should do to improve personal budget delivery but it can certainly help and be used alongside other information and evidence.

The current National Personal Budget Survey findings point to a number of actions councils might take or explore locally. Councils and other organisations are now starting to use POET and local findings in a range of ways including:

- Holding local engagement and planning sessions with managers, professionals, personal budget holders and their families. These can look at the POET findings, make comparisons with findings in other councils and set them against other local data, experiences and perspectives. Councils can then develop personal budget improvement plans as part of broader local activity and Care Act delivery arrangements.
- Some councils have used POET findings as part of wider local stakeholder engagement and planning using the *Making it Real* markers. The findings can be used to inform the part of *Making it Real* reviews and planning that focus on personal budgets and can also inform other elements, including information and advice.
- In some places councils are looking to incorporate POET within regular processes for checking user experience and outcomes – for example via the review process. In this way local personal budget delivery and wider commissioning activity can be systematically informed by direct user feedback.

Inevitably as we build the practice evidence from POET, not all findings are easily explained or can be used in a straightforward way to guide local activity. Accepting this caveat, however, we have outlined below some of the emerging themes and how councils and other organisations can potentially make use of them.

Finding	How might councils use findings?	What can TLAP offer?
<p>Most personal budget users and carers said personal budgets had made things better in the majority of life areas.</p>	<p>This is clearly an encouraging finding. Councils using POET locally can check how they performed against others to see if they achieved as well in these areas and target improvement in those where they did not.</p>	<p>Support for the use of POET across English councils is featured in the Personalisation Action Plan and the Care Services Minister has written to council directors to set out how they can be supported to use it in 2014/5.</p>
<p>Generally, there were not dramatic differences in reported outcomes across groups of people.</p>	<p>Councils using POET locally can check if this holds true locally. If it does not for some group, they can target improvements in groups not served as well locally.</p>	<p>TLAP has produced a range of materials setting out how councils can ensure that personal budgets can benefit different groups of people. These can be found in the self-directed support section of the TLAP website along with links to other useful materials from our partner organisations. Please see www.thinklocalactpersonal.org.uk/Browse/SDSandpersonalbudgets/</p>
<p>In this year's survey for most types of personal budget, (direct payment, council managed, or individual service fund) there were relatively few associations with outcomes.</p>	<p>Councils using POET will want to check if this finding holds true in their area. In other surveys people using direct payments have reported better outcomes in some areas of life. Councils will want to make sure that they are maximising choice, control and outcomes however people are choosing to have their personal budget held and managed.</p>	<p>The TLAP website contains a series of products and links setting out approaches to improve the delivery of personal budgets using direct payments, managed personal budgets and individual service funds. TLAP has also recently commissioned further work on individual service funds due for publication in early 2015. Please see www.thinklocalactpersonal.org.uk/Browse/SDSandpersonalbudgets/</p>

<p>A significant number found all or many aspects of the process difficult. Conversely, the process being easy was associated with positive results in all of the outcome indicators where measurement was possible.</p>	<p>Councils can look at the detail of these findings and explore how elements of local personal budget process compare. They can then look to address either/or end to end process or specific local elements that may need attention.</p>	<p>There is a range of materials on the TLAP site based on the gathering of promising practice from councils working to improve local process. TLAP has also commissioned an update of its <i>Minimum Process Framework</i> guidance for publication early in the New Year. Please see www.thinklocalactpersonal.org.uk/Browse/SDSandpersonalbudgets/</p>
<p>People's involvement in the personal budget process showed the biggest and most wide-ranging associations with positive outcomes. People who felt their views were fully included when their needs were being assessed were more likely to report positive impacts of their budget on 14 of the 15 outcome indicators.</p>	<p>Given the very strong association between these process conditions and outcomes, councils can prioritise good practice in these areas to achieve good results.</p> <p>They can look at the detail of the issues reported by personal budget holders and carers in the narrative responses to the POET survey and can explore similar issues locally with personal budget holders and staff.</p>	
<p>People who felt their views were fully included when the amount of the budget was set and people who felt their views were fully included when their support plan was written, were more likely to report positive impacts of their budget on all outcome indicators.</p>	<p>Councils can also look at practice approaches from other authorities which seem to be achieving better results in specific areas.</p>	<p>TLAP has published and linked to practical materials and tools which share promising approaches to support planning and have commissioned further guidance linked to Care Act delivery, for publication early in the New Year. Please see www.thinklocalactpersonal.org.uk/Browse/SDSandpersonalbudgets/</p>
<p>People who received no help to plan at all were least likely to report positive results across most life areas when compared with those who had some form of planning assistance.</p>		

<p>Carers who could report the amount of the person's budget were more likely to report positive impacts of the budget across most outcome indicators. Personal budget holders who could report the amount of their personal budget were more likely to report positive impacts of their budget in several life areas.</p>	<p>Though definitions of self-directed support include that people should know how much money is in their budget and this is an expectation under the Care Act, our survey shows that too few people know this information. Councils should make sure that they do, especially as there appears to be an association with some outcomes.</p>	<p>TLAP has consistently stressed that it is important for people to know the amount in their personal budgets and will continue to emphasise this in our work with the National Programme Office relating to Care Act delivery. For more information on the Care Act support programme, please see www.local.gov.uk/care-support-reform</p>
<p>In some significant areas of life, people who reported they were using their personal budgets on personal assistants and community and leisure activities reported better outcomes than when people used them on 'traditional' care services.</p>	<p>This finding would seem to support the importance of councils using information about personal budgets use to steer local commissioning practice and to ensure that 'non-traditional' options and good availability of quality personal assistance is present locally.</p>	<p>TLAP has published and linked to via its site, materials on commissioning for personalisation, developing and sustaining a diversity of provision and approaches to developing and sustaining a good quality supply of personal assistants. Please see www.thinklocalactpersonal.org.uk/Browse/marketdevelopment/ Further guidance on choice and diversity in provision has been commissioned for publication early in the New Year.</p>

Leeds has been using POET since Sept 2012 when 1,200 people with personal budgets were surveyed. Leeds held a follow up local engagement event which was facilitated by In Control in May 2013 with the aim of sharing the findings with stakeholders and to put together a co-produced improvement plan. The workshop was well attended by a mixed group of service users, carers, providers, personal assistants and council officers. For more information see Appendix 3.

6 DETAILED FINDINGS: PERSONAL BUDGET HOLDERS

This section of the report presents the detailed findings for personal budget holders responding to the POET survey. 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.

The findings include:

- Why people using personal budgets needed support.
- How people are managing their personal budget.
- If people got any help from someone paid to support them before getting a personal budget.
- How much money was allocated to them in their personal budget.
- How people were supporting in planning to use their personal budget.
- If the personal budget process was difficult.
- How people used their personal budget.
- If their personal budget had made a difference to their lives.

Who responded to the POET survey?

A total of 2,679 personal budget holders completed the POET survey and gave their agreement for the information to be used. Just under a third of personal budget holders (29.7%) answered the POET survey on their own and another third (31.9%) of people said they had some help from another person to complete the survey. A quarter (27.8%) of the surveys returned were completed by someone else on behalf of the personal budget holder. A small number completed the survey in a meeting or interview (10.5%).

EQUALITIES MONITORING INFORMATION

Full details are presented in Appendix 1.

- More women (57.8%) than men (42.2%) responded to the survey.
- In terms of age, almost a third (31.4%) of personal budget holders were aged 16-44 years, just under a third (30.3%) were aged 45-64 years, the remainder (38.3%) were aged 65 years or over.
- A vast majority of respondents were White (92.1%), with a minority of people from other ethnic groups (7.8%).
- More than half of respondents were Christian (63.1%), with over a quarter (27.2%) of respondents reporting themselves to have no religion.
- Three quarters of people reported themselves to be heterosexual/straight (75.2%), with a significant number (22%) indicating they did not wish to say.

Why did people using personal budgets need support?

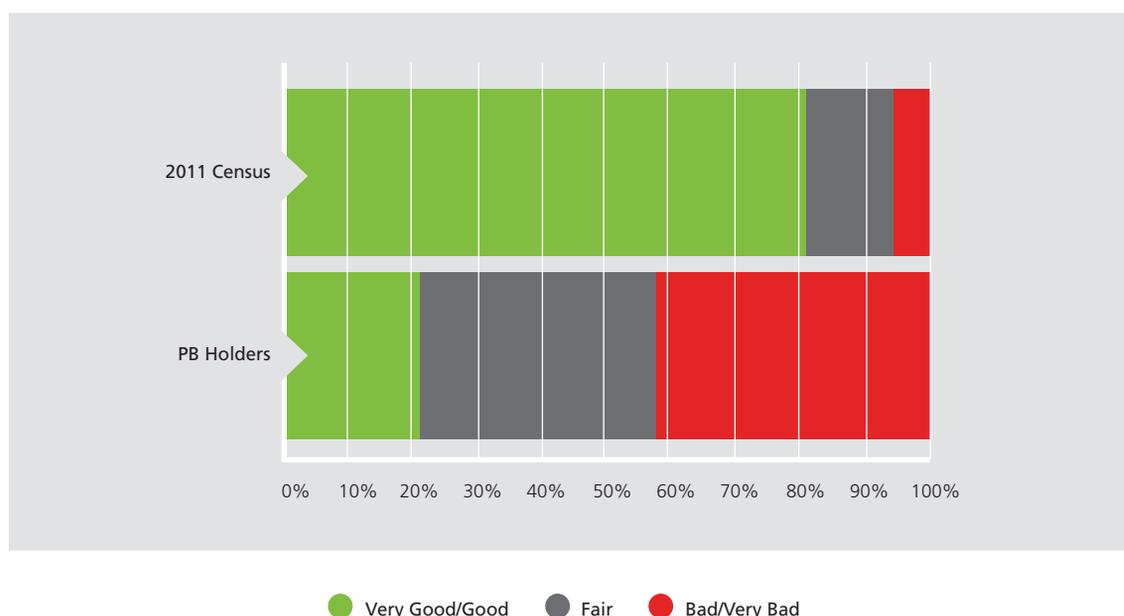
The POET survey for personal budget holders also asked people to state the main reason for which they were getting a personal budget. The most common reason people gave for having a personal budget was physical disability (40.3%), followed by learning disability (20.3%), complex health needs (15.6%) and old age (10.5%). Other main reasons given were mental health difficulties (8.7%), substance misuse (1%), sensory disability (1.2%) or another reason (2.6%).

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 opposite shows, the personal budget holders responding to the POET survey reported their health as much poorer than the general population in England⁹. Less than a third (31.6%) of personal budget holders reported their health as good or very good, compared to over three-quarters (81.4%) of the general population, and a third (32.8%) of personal budget holders reported their health as bad or very bad compared to 5.4% of the general population.

⁹ 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

Among POET respondents, people with learning disabilities were most likely to report better health and people with mental health difficulties were most likely to report poorer health¹⁰.

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



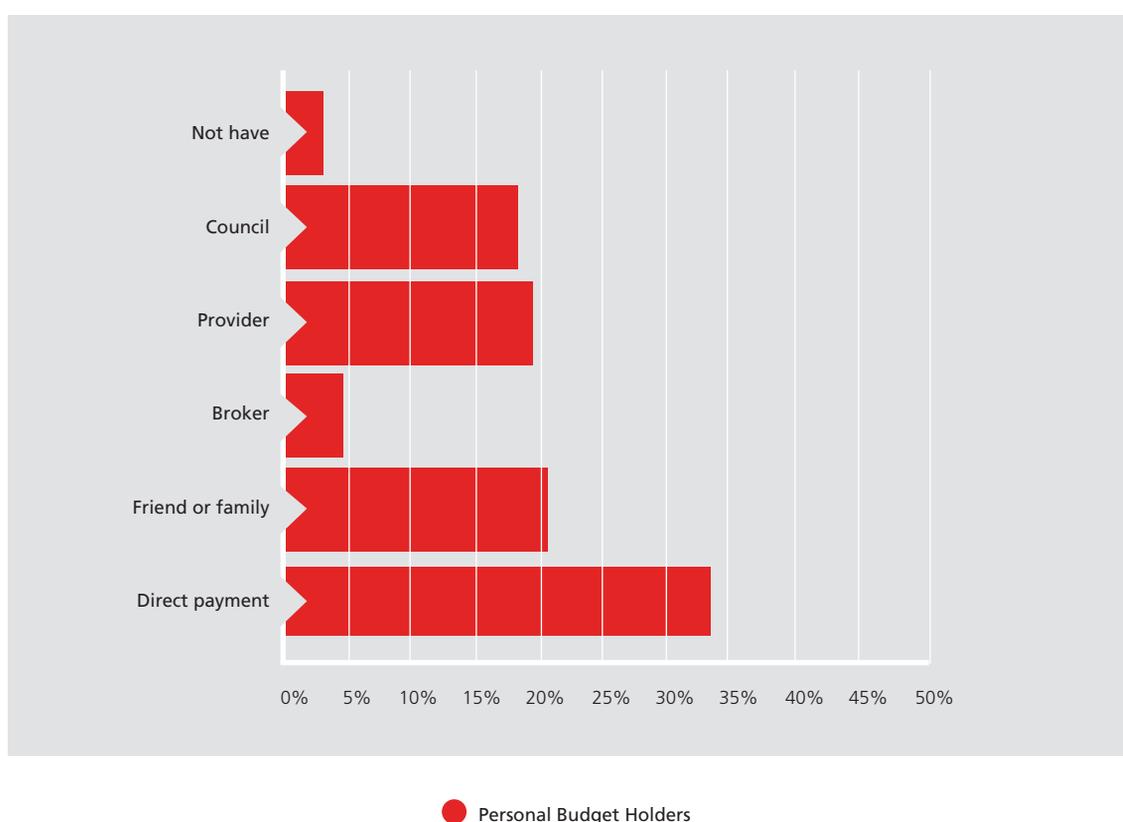
How do people manage their personal budgets?

Figure 2 overleaf shows the different ways that people responding to the POET survey managed their personal budgets. People most commonly managed their personal budget through direct payments paid to them (33.4%), followed by direct payments looked after by a friend or family member (20.5%). Personal budgets managed by a provider (19.7%), council or NHS-managed personal budgets (18.3%) and personal budgets managed by a broker (5%) were less common. A small number (3%) of respondents said they had not been given a personal budget.

¹⁰ One-way ANOVA. $F=72.3$; $df=3$, 1997; $p<0.001$

People with learning disabilities were less likely than other groups to have a direct payment made straight to them¹¹ and more likely than other groups to have a direct payment paid to a family member or friend¹². People with physical disabilities were more likely than other groups to have a budget managed by a broker¹³. Older people were less likely than other groups to have a budget managed by a service provider¹⁴. Older people were more likely and people with physical disabilities were less likely, to report not having a personal budget at all¹⁵. There were no differences across groups in the proportion of people having a council-managed personal budget.

FIGURE 2: Management of personal budget



11 *Chi square=99.5; df=3, p<0.001*

12 *Chi square=92.4; df=3, p<0.001*

13 *Chi square=11.2; df=3; p=0.011*

14 *Chi square=33.5; df=3, p<0.001*

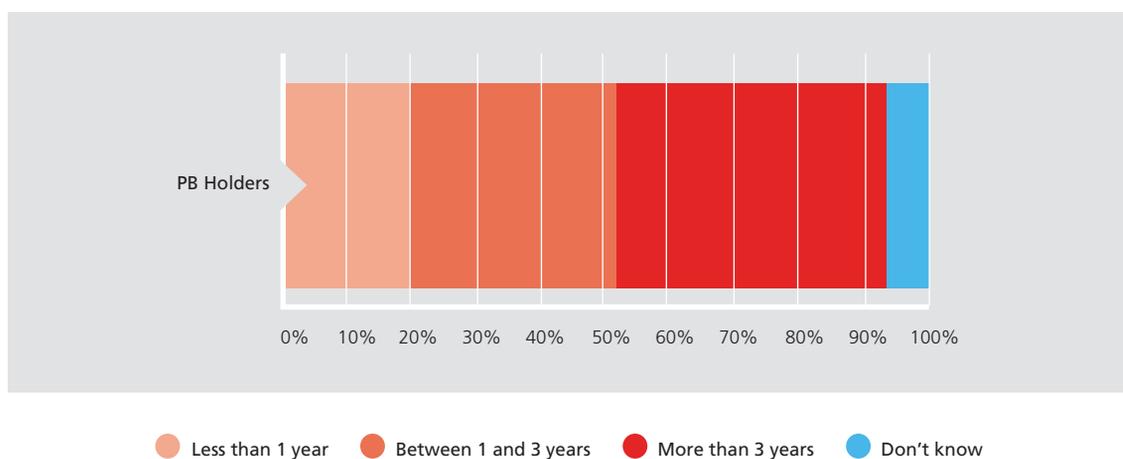
15 *Chi square=17.6; df=3, p<0.001*

How long have people held a personal budget?

Figure 3 shows how long POET survey respondents have held their personal budget. Most commonly respondents had held their personal budget for more than three years (38.7%), followed by those who had held their budget between one and three years (34.5%), people holding their budget for less than a year accounted for 19.3 %, and finally a small number did not know how long they had held their budget (7.5%).

Older people were more likely to have held their personal budget for a shorter period of time than other groups¹⁶.

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

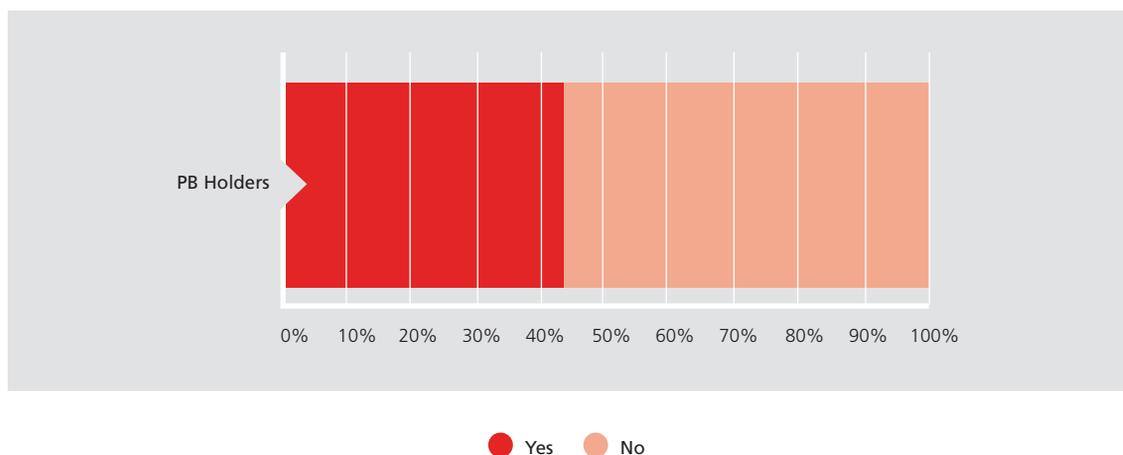


Did people receive a service or get any help from someone who was paid to support them before getting a personal budget?

Figure 4 overleaf shows how many personal budget holders had been receiving help from someone who was paid to support them before getting their personal budget. Respondents were quite evenly split with under half (43.2%) of respondents having received social care support before the start of their personal budget. There were no differences across groups in the proportion of people receiving social care support before their personal budget.

¹⁶ Chi square=20.86; df=6, p=0.002

FIGURE 4: Previous social care support before the personal budget



The cost of personal budgets

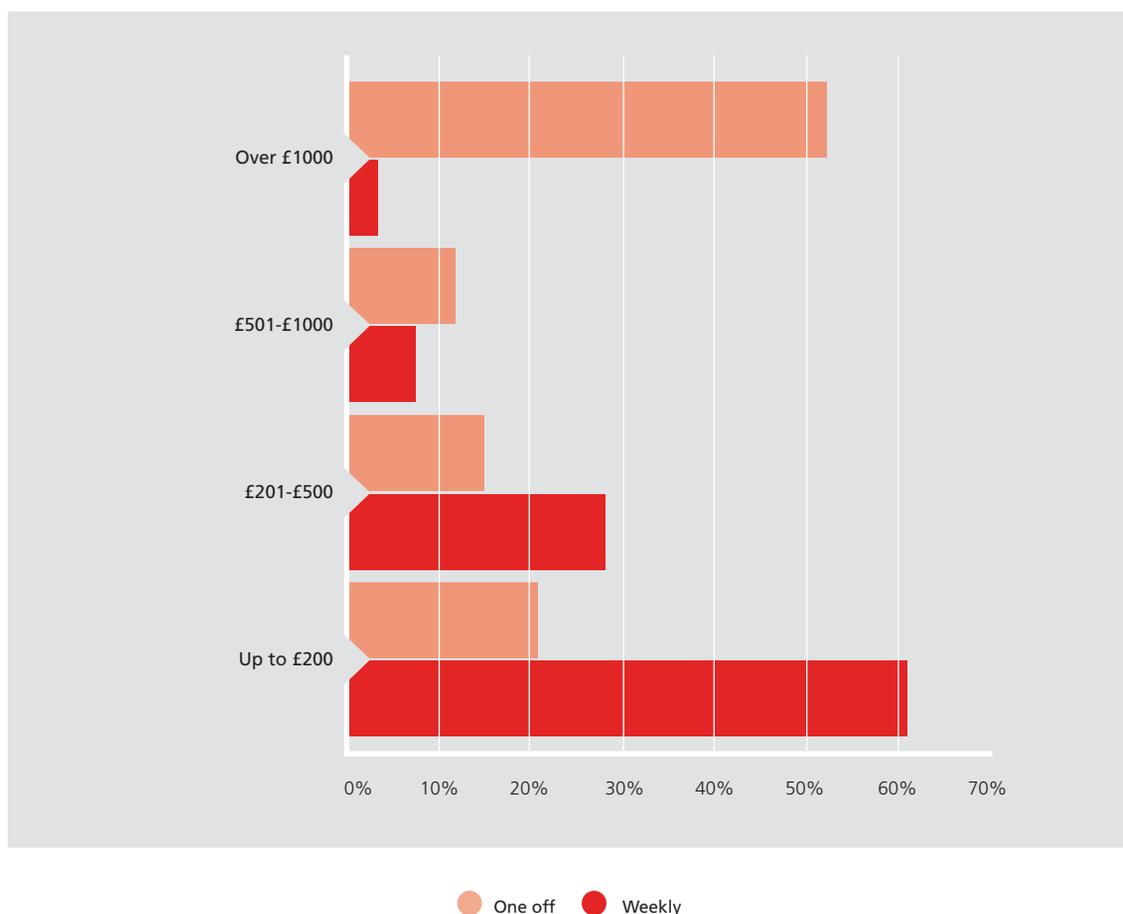
The POET survey asked personal budget holders to say how much money they had been allocated and whether this was a regular or one off payment. Half the personal budget holders responding to the survey (49.2%) said how much money they had been allocated. The overwhelming majority (90.7%) who provided a figure, report an ongoing payment, the remainder were given a one off payment (9.3%).

Figure 5 opposite shows that of the 1,205 people reporting a weekly amount for their personal budget: the majority (61.2%) reported a budget up to £200 per week; just over a quarter (28.3%) between £201 and £500 per week; a small number (7.3%) between £501 and £1,000 per week and (3.2%) more than £1,000 per week. For ongoing personal budgets, people with mental health difficulties reported the lowest weekly amount (average £191 per week), then older people (average £205 per week) and people with learning disabilities (average £279 per week), with people with physical disabilities reporting the highest weekly amount (average £319 per week)¹⁷.

Of the 126 people reporting a one-off payment: just over half (52.4%) reported a payment of more than £1000; the other half were broadly evenly spread; up to £200 (20.6%), £201-£500 (15.1%) and £501-£1000 (11.9%).

17 One-way ANOVA $F=8.5$; $df=3$, 1015; $p<0.001$

FIGURE 5: Amount of money in personal budgets



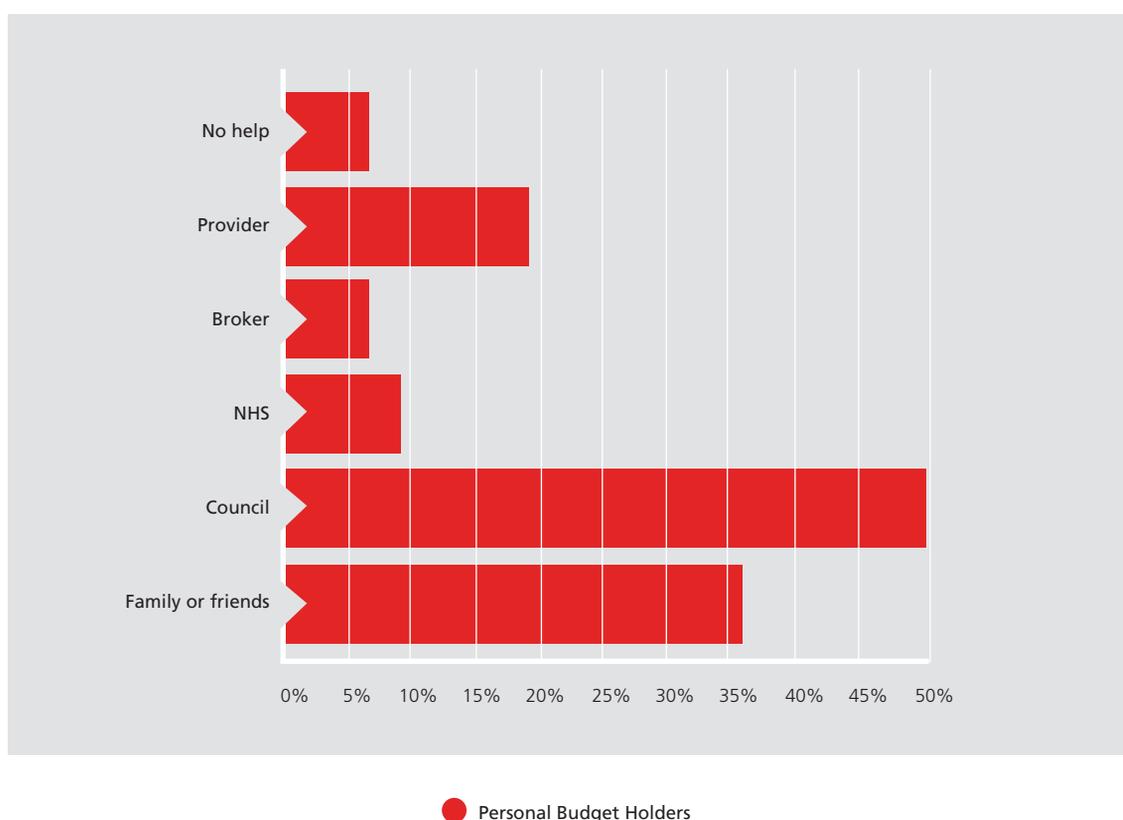
Support for planning personal budgets

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

Figure 6 overleaf shows how many people used various sources of support in planning how to use their personal budget, respondents could indicate they had support from more than one source. The three main areas of support were from the council (49.9%), family or friends (35.2%), and from providers (18.7%) with support to plan from other areas also available to some people (brokers (6.2%), NHS (9.2%)); 6.2% of people said they had no help to plan.

People with learning disabilities and older adults were more likely than people with physical disabilities or people with mental health difficulties to report getting help to plan from family or friends¹⁸. People with mental health difficulties were more likely than other groups to get support to plan from the NHS¹⁹ and from a broker²⁰. Older people were less likely than other groups to get support to plan from a service provider²¹. People with learning disabilities were less likely than other groups to do their planning themselves without help²². There were no differences across groups in the proportion of people getting help to plan from the council.

FIGURE 6: Support for planning personal budgets



18 *Chi square*=46.2; *df*=3; *p*<0.001

19 *Chi square*=45.2; *df*=3; *p*<0.001

20 *Chi square*=18.4; *df*=3; *p*<0.001

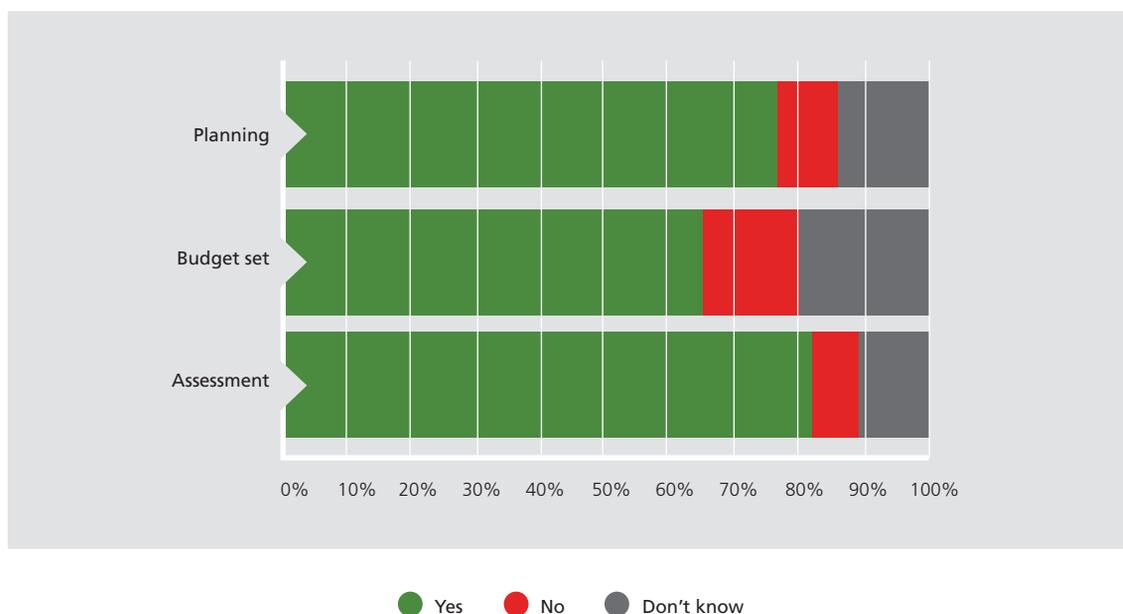
21 *Chi square*=41.2; *df*=3; *p*<0.001

22 *Chi square*=16.4; *df*=3; *p*<0.001

The POET survey asked respondents whether their views were included in various aspects of the personal budget process (see Figure 7). The majority of personal budget holders reported their views had been included when their needs were assessed (82%) and when their plan was developed (76.9%); a less substantial majority reported their views had been included when their budget was set (65.1%).

People with mental health difficulties were less likely than other groups to say that their views had been included when their needs were assessed²³. People with physical disabilities were more likely than other groups to say that their views had been included when their personal budget was set²⁴. There were no differences across groups in the proportion of people saying that their views had been fully included when their support plan was written.

FIGURE 7: People’s views included in the personal budget process



²³ Chi square=11.1; df=3; p=0.011

²⁴ Chi square=22.1; df=3; p<0.001

Was the personal budget process difficult for people?

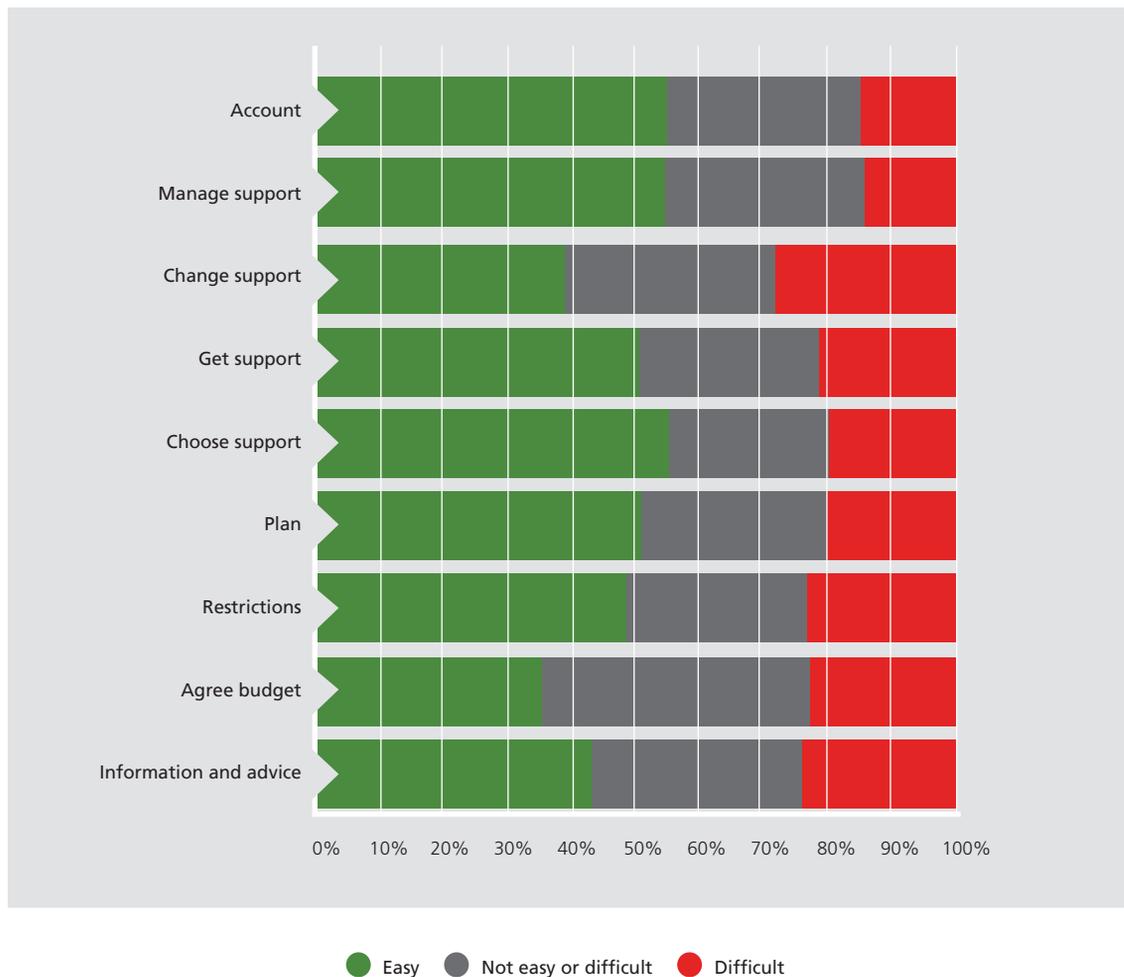
As Figure 8 opposite shows, the POET survey asked several questions to personal budget holders about whether various aspects of the personal budget process were easy or not for them. Respondents were given an option to say if an area of the process being asked about was not applicable to them. Here percentages shown are of those saying that aspect of process was relevant to them.

Around a quarter of personal budget holders said that aspects of the process were difficult for them in three of nine areas we asked about: making changes to support (28.4%); information and advice (24.1%); and understanding restrictions placed on the use of the personal budget (23.6%). A significant minority of people also found other aspects of the personal budget process difficult; agreeing the budget (22.9%), getting support (21.2%), choosing support (19.5%) and planning support (19.5%).

In terms of differences between groups, there was a consistent pattern across all the ways that councils could make things easy or difficult for people: people with learning disabilities and people with mental health difficulties were more likely to report that the council made things difficult, older people were more likely to report the council making things neither easy nor difficult, and people with physical disabilities were more likely to report that the council made things easy²⁵.

25 *Information and advice: chi square=62.8; df=6; p<0.001; Agree amount: chi square=49.5; df=6; p<0.001; Understand what budget can be spent on: chi square=50.2; df=6; p<0.001; Support planning: chi square=59.2; df=6; p<0.001; Choose support: chi square=49.1; df=6; p<0.001; Get the support wanted: chi square=49.0; df=6; p<0.001; Change support: chi square=34.2; df=6; p<0.001; Manage support from day to day: chi square=22.7; df=6; p<0.001; Account for how the budget is spent: chi square=44.1; df=6; p<0.001*

FIGURE 8: The personal budget process

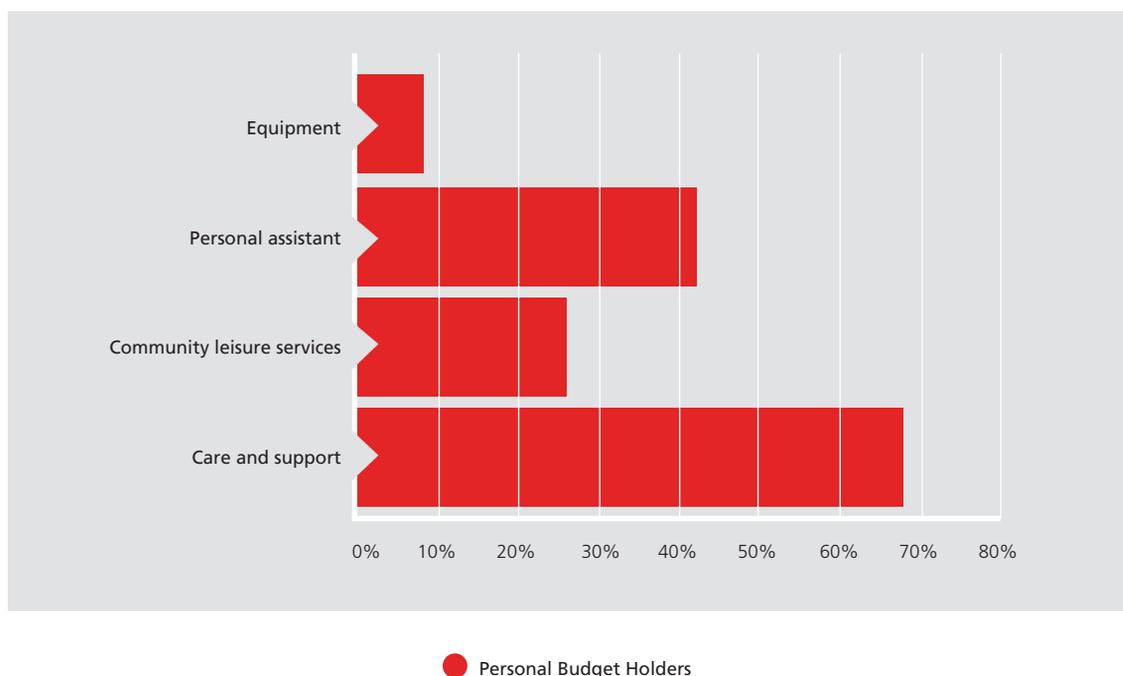


How have people used their personal budgets?

We asked personal budget holders how they had used their personal 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 9 overleaf shows that significant numbers of personal budget holders use their budget in all these ways. The most common way to use their budget was on care and support services (67.8%), followed by a personal assistant (42.2%), community and leisure services (25.8%), and for equipment (8.4%).

Older people, followed by people with mental health difficulties, then people with learning disabilities and people with physical disabilities, were more likely to use their budget for a care and support service²⁶. People with learning disabilities, followed by people with mental health difficulties, then people with physical disabilities, then older people, were more likely to use their budget for a community and leisure service²⁷. People with physical disabilities, followed by people with learning disabilities and people with mental health difficulties, then older people, were more likely to use their budget for a personal assistant²⁸. Older people, followed by people with physical disabilities, then people with mental health difficulties, then people with learning disabilities, were more likely to use their budget for equipment²⁹.

FIGURE 9: How personal budget holders' used their budget



²⁶ Chi square=76.0; df=3; p<0.001

²⁷ Chi square=182.7; df=3; p<0.001

²⁸ Chi square=163.9; df=3; p<0.001

²⁹ Chi square=20.1; df=3; p<0.001

Have personal budgets made a difference to people’s lives?

The POET survey asks personal budget holders whether their personal 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 budgets on the 15 areas of people’s lives we asked about.

FIGURE 10: Areas of life: personal budget holders

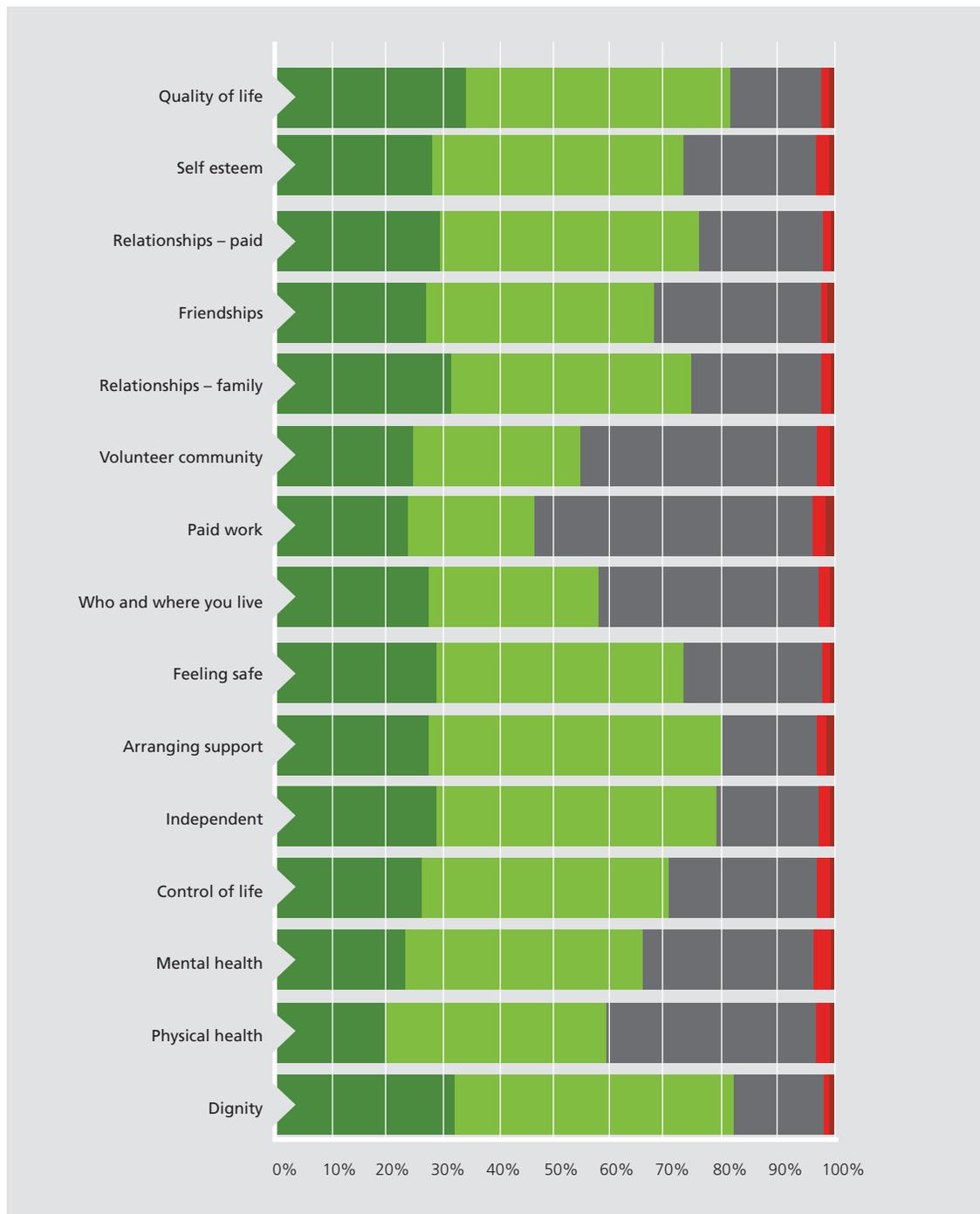
1) Being supported with dignity and respect	2) Your physical health	3) Your mental health
4) Being in control of important things in your life	5) Staying as independent as you want to be	6) Arranging the support you need
7) Feeling safe (at home and when you go out)	8) Choosing where you live or who you live with	9) Getting and/or keeping a paid job
10) Doing things like volunteering that help your local community	11) Your relationship with your family carer	12) Your relationships with your other family and friends
13) Your relationships with people paid to support you	14) Your self esteem	15) Your quality of life

Again in this section of the report, survey 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 three quarters of personal budget holders reported their budget having a positive impact on five of the 15 areas we asked about: dignity (82%); independence (78.9%); arranging support (79.9%); paid relationships (75.9%) and quality of life (81.4%). In addition at least two thirds of personal budget holders reported their budget having a positive impact on a further six of the 15 areas of life we asked about: mental health (65.5%); control over life (70.6%); feeling safe (72.8%); family relationships (74.6%); friendships (67.8%); and self-esteem (73.2%). Finally more than half of personal budget holders reported their budget having a positive impact on three more areas: physical health (59.9%); with who and where you live (57.9%); and volunteering and community (54.6%).

Overall, small numbers of people reported their personal budget having a negative impact on any of these 15 aspects of people’s lives; the lowest being dignity in support (1.9%) and the highest being mental health (4.2%).

FIGURE 11: Difference personal budgets have made to lives of personal budget holders



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

Differences in outcomes across groups of people

There were no differences in groups in the reported positive impact of their budget on: being supported with dignity; physical health; arranging support; feeling safe; where you live and who you live with; volunteering; relationships with the person's paid supporters; and quality of life. Older people were less likely than other groups to report a positive impact of their budget on their mental health³⁰.

Older people were less likely, and people with physical disabilities, more likely to report a positive impact of their budget on the degree to which they had control over their life³¹.

People with learning disabilities were less likely and people with physical disabilities were more likely to report a positive impact of their budget on being as independent as they wanted to be³².

Older people and people with physical disabilities were more likely than people with learning disabilities or people with mental health difficulties to report a positive impact of their budget on their capacity to undertake paid work³³.

People with mental health difficulties were more likely than other groups to report a positive impact of their budget on their relationship with their main family carer³⁴.

People with mental health difficulties and people with physical disabilities were more likely to report a positive impact of their budget on their relationships with other family and friends³⁵.

People with learning disabilities and people with mental health problems were less likely to report a positive impact of their budget on their self-esteem than people with learning disabilities and older people³⁶.

As noted earlier, relatively few people reported a negative impact of their budget on any aspect of their lives.

30 *Chi square=25.9; df=3; p<0.001*

31 *Chi square=30.0; df=3; p<0.001*

32 *Chi square=11.9; df=3; p=0.008*

33 *Chi square=10.3; df=3; p=0.016*

34 *Chi square=9.0; df=3; p=0.029*

35 *Chi square=18.4; df=3; p<0.001*

36 *Chi square=19.4; df=3; p<0.001*

People with mental health difficulties were slightly more likely than other groups to report a negative impact of their budget on being supported with dignity³⁷, their relationships with other family members and friends³⁸, their relationships with others paid to support them³⁹ and their quality of life⁴⁰.

People with mental health difficulties and people with physical disabilities were slightly more likely than other groups to report a negative impact of their budget on the degree of control they had over their lives⁴¹ and arranging their support⁴².

People with learning disabilities and people with mental health difficulties were slightly more likely than other groups to report a negative impact of their budget on where and who people lived with⁴³.

There were no differences between groups in reporting of negative impacts of their budget on their: physical health; mental health; being as independent as they wanted to be; feeling safe; getting and keeping paid work; volunteering; relationships with the person's main family carer; and self-esteem.

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

Respondents were asked to comment about their experience of having a personal 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 (76.0%), 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.

37 *Chi square=8.4; df=3; p=0.039*

38 *Chi square=8.8; df=3; p=0.032*

39 *Chi square=17.6; df=3; p=0.001*

40 *Chi square=10.2; df=3; p=0.017*

41 *Chi square=7.9; df=3; p=0.049*

42 *Chi square=9.6; df=3; p=0.022*

43 *Chi square=9.6; df=3; p=0.023*

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 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	
Support	The nature, location, timing, and type of treatment or support available as a result of the personal budget.
Choice/control	The degree of choice and control the personal budget had allowed over treatment and support, and in other aspects of life.
Independence	The impact of the personal 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.
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.
Positive	Expression of gratitude or non-specific positive comments
Process	The experience of getting and controlling a budget. In particular the paperwork involved in applying for or accounting for a budget.
Home	The impact of the personal budget on the person's home life.
Carer	Impact of the personal budget on the life of the person's carer.
Health	The impact that the personal 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.
Staff	The knowledge, understanding, attitudes of staff – mainly council staff responsible for referrals, assessments and support planning.
Review	The frequency and infrequency of reviews, the anxiety caused by prospect of losing resources following review.
Set up	The difficulty in spending the personal budget and identifying and recruiting staff.
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.
Timeliness	Speed with which the personal budget was allocated and the time it took to establish an appropriate support package.
Managing budget	The experience of controlling and accounting for a personal budget.
Communication	The experience of communicating with staff, in particular difficulty accessing individuals. The impact of communication between organisations.
Advice	Information, advice, guidance and support available to people taking control of a personal 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.
Funding/service Level	The amount of money in the budget or service available as a result of having a budget.

Factors associated with positive outcomes for personal budget holders

Figure 11 on page 30 shows how personal budget holders feel their personal budget has affected (or not) 15 areas of their lives. In this section of the report we ask four further questions:

- 1) Are there differences in the outcomes of personal budgets depending on gender, ethnicity, need for social care support or current health status?
- 2) Are aspects of the personal budget (organisation administering the personal budget, previous local authority support, length of time with personal budget, knowing the amount of the personal budget, type of personal budget) associated with positive outcomes?
- 3) Are personal budget holders' perceptions of the processes involved in holding a personal budget (support in personal budget planning; feeling that your views are included throughout the process; feeling that the council makes the personal budget process easy) associated with positive outcomes?
- 4) Are what people have spent their personal 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 budget, what the odds of them reporting a positive impact of their personal 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 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 when interpreting the results we report over the following pages.

It is also important to note that these analyses have only been conducted where people have rated the outcome indicator as relevant to them.

The tables on the following pages 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 and that cell is shaded green for a positive relationship and red for a negative relationship. All of these significant associations are reported in the text.

FIGURE 12: Personal budget holders' comments on what worked well, what didn't work well and what should change

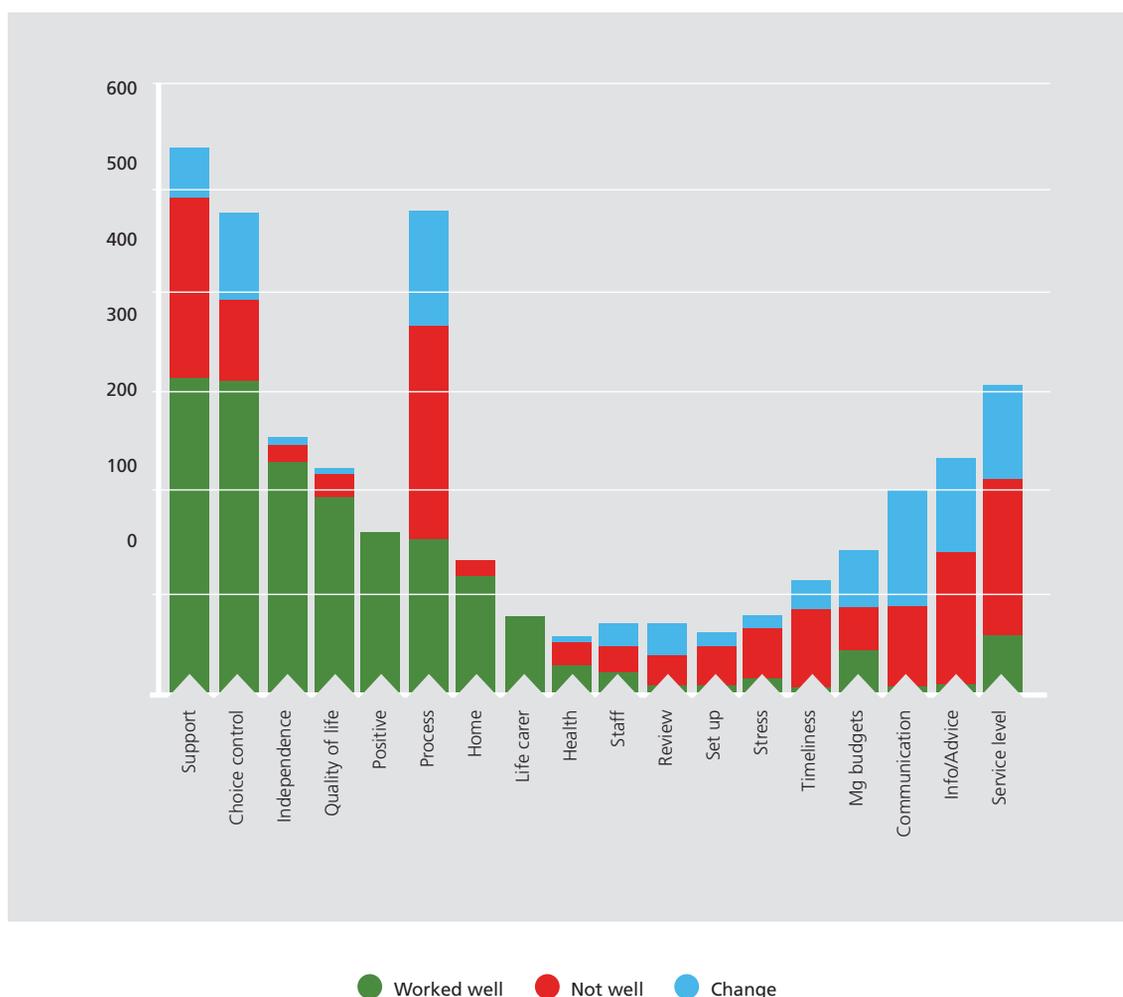


Table 1 overleaf shows associations between personal factors and positive impacts of personal budgets.

There were few associations between gender, ethnicity or self-reported health and outcomes. Women were more likely to report a positive impact of their budget on feeling safe and the extent of control they had over their life. People from minority ethnic communities were more likely to report a positive impact of their budget on their physical health. People with self-rated 'fair to poor' health were more likely to report a positive impact of their budget on their relationships with friends and being supported with dignity.

In terms of reported need for social care support, older adults were less likely to report a positive impact of their budget on their self-esteem, their relationships with friends, the extent of control over their lives and their mental health. Those older adults who felt that paid work was relevant to them were, however, more likely to report a positive impact of their budget on their opportunities for paid work.

People with learning disabilities were less likely to report a positive impact of their budget on their opportunities for paid work, feeling safe, being as independent as they wanted to be and being supported with dignity. They were, however, more likely to report a positive impact of their budget on their self-esteem.

People with mental health difficulties were more likely to report a positive impact of their personal budget on their relationships with friends and with family, and on their mental health.

People with physical disabilities were more likely to report a positive impact of their personal budget on their quality of life, their self-esteem, their relationships with friends, being as independent as they wanted to be and the extent of control they had over their life.

TABLE 1: Associations between personal factors and positive impacts of personal budgets

Outcome	Factors potentially associated with outcomes: Personal factors						
	Female gender	White	Older adult (aged 65 years+)	Person with learning disabilities	Person with mental health difficulties	Person with physical disabilities	Fair/bad/very bad self-rated health
Quality of life	1.02	0.97	0.81	1.06	0.91	1.37*	0.95
Self-esteem	0.94	0.79	0.67*	1.39*	0.85	1.39*	1.00
Relationships-paid	0.99	0.78	0.91	1.07	1.21	0.95	1.20
Friends	1.08	0.83	0.69*	1.01	1.44*	1.40*	1.13
Relationships-family	0.98	0.86	0.89	0.83	1.73*	1.14	1.36*
Volunteer-community	1.21	1.33	0.99	0.96	0.89	1.14	1.10
Paid work	1.39	1.23	1.79*	0.58*	0.62	1.23	1.05
Where & who you live with	1.25	0.82	1.14	0.81	0.84	1.13	1.23
Feeling safe	1.24*	0.91	1.13	0.77*	1.10	1.10	1.20
Arranging support	1.02	0.99	1.04	0.86	1.17	1.04	1.18
Independence	1.10	0.99	1.01	0.72*	1.06	1.47*	1.22
Control over life	1.27*	0.87	0.60*	1.09	1.25	1.74*	0.95
Mental health	1.13	0.94	0.60*	1.24	1.51*	1.28	1.01
Physical health	0.98	0.69*	0.92	1.01	1.09	1.06	1.06
Dignity	1.08	0.83	1.06	0.78*	1.13	1.17	1.35*

Table 2 overleaf shows associations between various aspects of the personal budget and positive impacts of personal budgets.

In terms of the organisation funding the personal budget, people with a personal budget funded by the council were more likely to report positive impacts on relationships with family, feeling safe, being as independent as they wanted to be, the extent of control over their lives, their mental health, and being supported with dignity. People with a personal budget funded by the NHS were more likely to report a positive impact of their budget on arranging their support. However, people with a budget funded by both the NHS and the council were less likely to report a positive impact of their budget on their mental health.

People who had not been supported by the council before their personal budget were more likely to report positive impacts of their budgets on their self-esteem, being as independent as they wanted to be and being supported with dignity.

People who had held their personal budget for more than a year were more likely to report positive impacts of their budget on 11 out of the 15 outcome indicators; this effect held for seven of the 15 outcome indicators amongst people who had held their budget for more than three years.

Finally, people who could report the amount of their personal budget (whether a weekly amount or a one-off payment) were more likely to report positive impacts of their budget on: their quality of life; arranging their support; being as independent as they wanted to be and their mental health.

TABLE 2: Associations between aspects of the personal budget and positive impacts of personal budgets

Outcome	Factors potentially associated with outcomes: The personal budget						
	NHS funding personal budget	Council funding personal budget	Both NHS and council funding personal budget	Council support before personal budget	Personal budget held for > 1 year	Personal budget held for > 3 years	Know amount of personal budget
Quality of life	1.82	0.98	0.84	0.82	1.48*	1.12	1.42*
Self-esteem	1.33	1.13	0.92	0.82*	1.50*	1.06	1.19
Relationships-paid	1.07	1.13	0.94	0.93	1.51*	1.48*	1.02
Friends	1.00	1.12	1.02	0.96	1.28*	1.35*	1.07
Relationships-family	0.82	1.35*	0.86	0.92	1.37*	1.38*	1.09
Volunteer-community	1.11	1.15	0.68	1.02	1.20	1.07	1.01
Paid work	0.58	1.39	0.47	0.74	1.45	1.29	0.99
Where & who you live with	0.83	1.24	1.05	1.03	1.70*	1.74*	0.86
Feeling safe	0.95	1.38*	0.78	0.83	1.60*	1.46*	1.09
Arranging support	1.91*	1.25	0.70	0.80	1.39*	1.53*	1.24*
Independence	1.19	1.36*	0.80	0.77*	1.33*	1.16	1.25*
Control over life	1.17	1.38*	0.87	0.86	1.34*	1.33*	1.19
Mental health	1.39	1.34*	0.63*	0.85	1.26	1.07	1.24*
Physical health	1.49	1.07	0.80	0.91	1.18	1.18	1.07
Dignity	0.75	1.51*	0.69	0.75*	1.50*	1.20	1.14

Table 3 overleaf shows associations between how the personal budget is held and positive impacts of personal budgets.

For most forms of personal budget, there were relatively few associations with outcomes.

People with their budget in the form of a direct payment paid directly to them were less likely to report positive impacts of their budgets on their relationships with friends and where and who they lived with. People with their budget in the form of a direct payment paid to a family member or friend were less likely to report positive impacts of their budgets on their relationships with family, the extent of control over their lives and their physical health. People with their budget organised by a broker reported no associations with outcomes, and people with a council/NHS managed budget were more likely to report a positive impact of their budget on where and who they lived with.

However, people with a budget managed by a provider were more likely to report positive impacts of their budgets on seven of the 15 outcome indicators: relationships with people paid to support them; friends and family members; arranging their support and being supported with dignity; and their mental and physical health. However, they were also less likely to report a positive impact of their budget on being as independent as they wanted to be.



TABLE 3: Associations between how the budget is held and positive impacts of personal budgets

Outcome	Factors potentially associated with outcomes: How the personal budget is held				
	Direct payment paid to own account	Direct payment paid to family or friend	Direct payment paid to broker	Provider-managed personal budget	NHS/council managed personal budget
Quality of life	1.05	0.87	1.16	1.13	1.18
Self-esteem	1.01	0.85	0.94	1.16	1.24
Relationships-paid	0.86	0.79	1.05	2.22*	0.85
Friends	0.82*	0.99	1.06	1.55*	1.08
Relationships-family	0.86	0.76*	0.88	2.08*	0.98
Volunteer-community	1.31	0.83	1.58	0.84	0.71
Paid work	1.02	0.85	0.84	1.02	0.86
Where & who you live with	0.79*	0.90	0.87	1.00	1.37*
Feeling safe	0.86	0.81	1.03	1.25	1.15
Arranging support	0.98	0.81	0.97	1.64*	0.93
Independence	1.23	0.90	0.97	0.79*	1.25
Control over life	1.22	0.73*	1.34	0.97	1.12
Mental health	0.83	0.80	0.94	1.94*	1.06
Physical health	0.92	0.68*	1.25	1.34*	1.20
Dignity	0.81	0.97	1.12	1.40*	1.13

Table 4 overleaf shows associations between who supported people to plan their budget and positive impacts of personal budgets.

People who were supported to plan by family and/or friends were less likely to report positive impacts of their budgets on their relationships with people paid to support them, their relationships with family members, arranging their support, and their physical and mental health.

Being supported to plan by someone from the council was not associated with any of the 15 outcome indicators. People who were supported to plan by someone from the NHS were less likely to report a positive impact of their budget on where and who they lived with.

People who were supported to plan by someone independent (such as a broker) were more likely to report positive impacts of their budget on their relationships with friends, feeling safe, and their mental health.

People who were supported to plan by their support provider were more likely to report positive impacts of their budget on their relationships with friends, where and who they lived with, feeling safe, the extent of control over their life, and their physical and mental health.

More than any specific source of support, however, being supported from any source was associated with the broadest range of outcome indicators. People who planned their support themselves without any help were less likely to report positive impacts of their budget on 13 out of the 15 outcome indicators.

TABLE 4: Associations between how people are supported to plan their budget and positive impacts of personal budgets

Outcome	Factors potentially associated with outcomes: Support in the personal budget planning process					
	Family/ friends help me to plan	Council helps me to plan	NHS helps me to plan	Independent person helps me to plan	Provider helps me to plan	Plan without help
Quality of life	1.15	1.04	1.06	1.28	1.25	0.57*
Self-esteem	0.99	1.07	1.18	1.15	1.28	0.64*
Relationships- paid	0.77*	1.13	1.03	1.53	1.16	0.64*
Friends	1.01	1.00	0.91	1.50*	1.41*	0.49*
Relationships- family	0.80*	1.12	0.96	1.57	1.23	0.52*
Volunteer- community	0.91	0.92	1.06	1.36	0.70	1.08
Paid work	0.89	1.02	0.98	1.28	1.05	0.71
Where & who you live with	0.90	0.85	0.64*	1.00	1.47*	0.61*
Feeling safe	0.85	1.00	1.26	1.61*	1.34*	0.54*
Arranging support	0.78*	1.20	1.25	1.44	1.06	0.66*
Independence	1.17	0.90	1.37	1.29	1.28	0.53*
Control over life	0.88	0.90	1.26	1.26	1.55*	0.63*
Mental health	0.69*	1.04	1.16	1.81*	1.34*	0.59*
Physical health	0.65*	1.04	1.05	1.32	1.30*	0.56*
Dignity	0.82	1.15	1.08	1.47	1.10	0.54*

Table 5 overleaf shows associations between people’s perceptions of the personal budget process and positive impacts of personal budgets.

These perceptions showed the consistently biggest and wide-ranging associations with outcome indicators. People who felt their views were fully included when their needs were being assessed were more likely to report positive impacts of their budget on 14 of the 15 outcome indicators. People who felt their views were fully included when the amount of the budget was set and people who felt their views were fully included when their support plan was written were more likely to report positive impacts of their budget on all 15 outcome indicators.

Finally, we asked people about whether the budget funder made nine aspects of the personal budget process easy or difficult. Because people’s scores across these nine aspects of process were highly associated⁴⁴, we combined them into one overall indicator of whether the budget funder made the process easy or not. Again, people who reported overall that the budget funder made the personal budget process easy were more likely to report positive impacts of their budget across all 15 outcome indicators.



People who felt their views were included during assessment, budget setting and planning were more likely to report positive outcomes

⁴⁴ Mean inter-item correlation=0.60

TABLE 5: Associations between perceptions of the personal budget process and positive impacts of personal budgets

Outcome	Factors potentially associated with outcomes: The personal budget process			
	Views included when needs assessed	Views included when budget amount was set	Views included when support plan written	Council/NHS made the personal budget process easy
Quality of life	2.88*	2.40*	2.57*	2.57*
Self-esteem	2.11*	2.19*	2.10*	2.32*
Relationships-paid	1.41*	1.72*	1.54*	2.35*
Friends	1.54*	1.66*	1.58*	2.00*
Relationships-family	1.41*	1.75*	1.47*	2.12*
Volunteer-community	1.70*	2.06*	1.76*	2.08*
Paid work	1.54	2.35*	1.68*	3.39*
Where & who you live with	1.37*	1.68*	1.80*	2.52*
Feeling safe	1.83*	2.02*	1.86*	2.39*
Arranging support	2.26*	2.29*	2.59*	2.79*
Independence	2.41*	1.61*	2.13*	2.07*
Control over life	2.28*	2.31*	2.46*	2.29*
Mental health	1.54*	1.74*	1.79*	2.15*
Physical health	1.60*	1.87*	1.89*	1.90*
Dignity	2.06*	1.79*	2.23*	2.43*

Table 6 overleaf shows associations between how people used their personal budget and positive impacts of personal budgets.

People using their budgets on care and support services were less likely to report positive impacts of their budgets on their quality of life, their self-esteem, their relationships with people paid to support them, the extent of control over their lives, their mental health and being supported with dignity. People using their budgets for equipment were less likely to report a positive impact of their budget on their relationships with people paid to support them.

In contrast, people using their budgets on community and leisure activities were more likely to report positive impacts of their budgets on: their quality of life; their self-esteem; their relationships with friends, family and people paid to support them; the extent of control over their lives and their mental health.

People using their budgets on personal assistants were more likely to report positive impacts of their budgets on 13 of the 15 outcome indicators.



TABLE 6: Associations between what the budget is spent on and positive impacts of personal budgets

Outcome	Factors potentially associated with outcomes: What the budget is spent on			
	Care and support	Community and leisure	Personal assistants	Equipment
Quality of life	0.73*	1.55*	2.23*	1.01
Self-esteem	0.71*	1.59*	1.93*	1.21
Relationships-paid	0.80*	1.33*	2.06*	0.61*
Friends	0.83	1.25*	1.72*	0.80
Relationships-family	0.84	1.31*	2.10*	0.81
Volunteer-community	0.84	1.01	1.50*	1.15
Paid work	0.85	0.84	1.41	0.92
Where & who you live with	0.97	0.86	1.23	0.89
Feeling safe	0.91	1.03	1.91*	0.96
Arranging support	0.87	1.21	2.28*	0.98
Independence	0.86	1.11	2.10*	0.89
Control over life	0.74*	1.35*	2.04*	0.88
Mental health	0.80*	1.51*	1.50*	0.77
Physical health	0.88	1.09	1.39*	0.90
Dignity	0.78*	1.13	1.60*	0.74

Which factors are most strongly associated with positive outcomes of personal budgets?

As tables 1 to 6 make clear, many factors were associated with positive outcomes of personal budgets. To explore which of these factors were most strongly associated with positive outcomes, we conducted a series of logistic regressions (one for each outcome indicator). These calculate which of all the factors listed in the tables above are statistically associated with the outcome indicator, while controlling for all the other factors potentially associated with that outcome indicator.

These analyses are exploratory, and it is important to bear the following issues in mind when interpreting the results. First, regressions are still associations – we cannot assume that the factor caused the positive outcome. Second, each regression requires a complete set of information for each person – because people could rate an outcome indicator as not relevant to them, their data could not be included in that regression equation. There were two outcome indicators (paid work and volunteering) where there were too few people for the regression to be robust, so regressions for these outcome indicators are not reported here. Finally, only factors with a strong association ($p < 0.01$) with the outcome indicator are reported in Table 7.

Table 7 shows some clear patterns in the factors most strongly associated with people's perceptions of positive outcomes from their personal budget.

Personal factors such as gender, ethnicity, age or self-reported social care need were extremely rarely associated with outcome indicators in the regressions, although poor self-reported health was associated with positive outcomes for three outcome indicators. Similarly the type of personal budget was also rarely associated with outcome indicators when other factors were taken into account, although having a provider-managed budget was associated with improved relationships with family and paid supporters.

Instead, particular aspects of the personal budget process were regularly associated with outcome indicators. The council/NHS making the personal budget process easy was associated with all of the 13 outcome indicators for which we could calculate regressions. People reporting that their views were fully included, particularly in budget setting and support planning, were associated with a smaller number of outcome indicators. Specific sources of support to plan were extremely rarely associated with outcomes.

In addition, what people spent their budget on was also associated with a range of outcome indicators. People who spent their budget on community/leisure activities

were more likely to report a positive impact of their budget on: their quality of life; self-esteem; being as independent as the person wants to be; control over the person's life and their mental health. People who spent their budget on personal assistants were more likely to report a positive impact of their budget on: their quality of life; self-esteem; relationships with paid supporters and family; feeling safe; arranging support; being as independent as the person wants to be; and control over the person's life. People who spent their budget on equipment were less likely to report positive outcomes across four outcome indicators, and spending the budget on care and support was not associated with any outcome indicators.

Finally, it is worth noting that better outcomes in quality of life and self-esteem were reported by people who had held their budget for more than a year, and a better outcome in where and who the person lived with was reported by people who had held their budget for more than three years.

TABLE 7: Logistic regressions: factors most strongly associated with positive outcomes

Factor	Corrected odds ratio (p)
Factors associated with positive impact of budget on quality of life (n=1,323; Nagelkerke R²=0.14)	
Have had personal budget for 1+ year	1.72 (p=0.007)
Council/NHS made the personal budget easy	2.13 (p<0.001)
Budget spent on community/leisure	1.72 (p=0.005)
Budget spent on personal assistants	2.00 (p<0.001)
Factors associated with positive impact of budget on self-esteem (n=1,294; Nagelkerke R²=0.17)	
Have had personal budget for 1+ year	1.75 (p=0.003)
Council/NHS made the personal budget easy	2.27 (p<0.001)
Budget spent on community/leisure	1.72 (p=0.001)
Budget spent on personal assistants	2.00 (p<0.001)

Factors associated with positive impact of budget on relationships with paid supporters (n=1,259; Nagelkerke R²=0.18)	
Fair/bad/very bad health	1.68 (p=0.002)
Provider-managed budget	1.45 (p=0.007)
Council/NHS made the personal budget easy	2.50 (p<0.001)
Views included in budget setting	1.72 (p=0.007)
Budget spent on personal assistants	2.04 (p<0.001)
Budget not spent on equipment	0.42 (p=0.001)
Factors associated with positive impact of budget on relationships with friends (n=1,263; Nagelkerke R²=0.15)	
Council/NHS made the personal budget easy	2.17 (p<0.001)
Views included in budget setting	2.00 (p<0.001)
Budget not spent on equipment	0.53 (p=0.009)
Factors associated with positive impact of budget on relationships with family (n=1,189; Nagelkerke R²=0.15)	
Fair/bad/very bad health	1.67 (p=0.002)
Provider-managed budget	2.86 (p=0.002)
Council/NHS made the personal budget easy	2.00 (p<0.001)
Budget spent on personal assistants	1.92 (p<0.001)
Factors associated with positive impact of budget on where and who the person lives with (n=789; Nagelkerke R²=0.20)	
Have had personal budget for 3+ years	1.72 (p=0.003)
Council/NHS made the personal budget easy	2.70 (p<0.001)
Factors associated with positive impact of budget on feeling safe (n=1,285; Nagelkerke R²=0.14)	
Council/NHS made the personal budget easy	2.27 (p<0.001)
Budget spent on personal assistants	2.17 (p<0.001)
Factors associated with positive impact of budget on arranging support (n=1,320; Nagelkerke R²=0.17)	
Council/NHS made the personal budget easy	2.22 (p<0.001)
Views included in support planning	2.00 (p=0.003)
Budget spent on personal assistants	2.63 (p<0.001)

Factors associated with positive impact of budget on being as independent as the person wants to be (n=1,326; Nagelkerke R²=0.14)	
Council/NHS made the personal budget easy	1.96 (p<0.001)
Budget spent on community/leisure	1.89 (p<0.001)
Budget spent on personal assistants	2.27 (p<0.001)
Budget not spent on equipment	0.49 (p=0.006)
Factors associated with positive impact of budget on control over the person's life (n=1,286; Nagelkerke R²=0.17)	
Female gender	1.45 (p=0.008)
Council/NHS made the personal budget easy	2.08 (p<0.001)
Budget spent on community/leisure	1.54 (p=0.007)
Budget spent on personal assistants	1.89 (p<0.001)
Factors associated with positive impact of budget on mental health (n=1,228; Nagelkerke R²=0.15)	
Council/NHS made the personal budget easy	2.13 (p<0.001)
Budget spent on community/leisure	1.59 (p=0.004)
Budget not spent on equipment	0.52 (p=0.007)
Factors associated with positive impact of budget on physical health (n=1,291; Nagelkerke R²=0.12)	
Family/friends did not help to plan	0.60 (p=0.001)
Council/NHS made the personal budget easy	1.82 (p<0.001)
Views included in support planning	1.96 (p=0.002)
Factors associated with positive impact of budget on being supported with dignity (n=1,357; Nagelkerke R²=0.14)	
Fair/bad/very bad health	0.58 (p=0.001)
Council/NHS made the personal budget easy	1.96 (p<0.001)
Views included in budget setting	1.79 (p=0.004)

7 DETAILED FINDINGS: CARERS

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

- Information about who carers are caring for, how much care they provide and whether they live with the person they care for.
- Information about the personal 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 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.
- What factors are associated with better outcomes for carers.

Who responded to the POET survey for carers?

In total, 1,328 carers from 19 council areas and 20 NHS organisations 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.

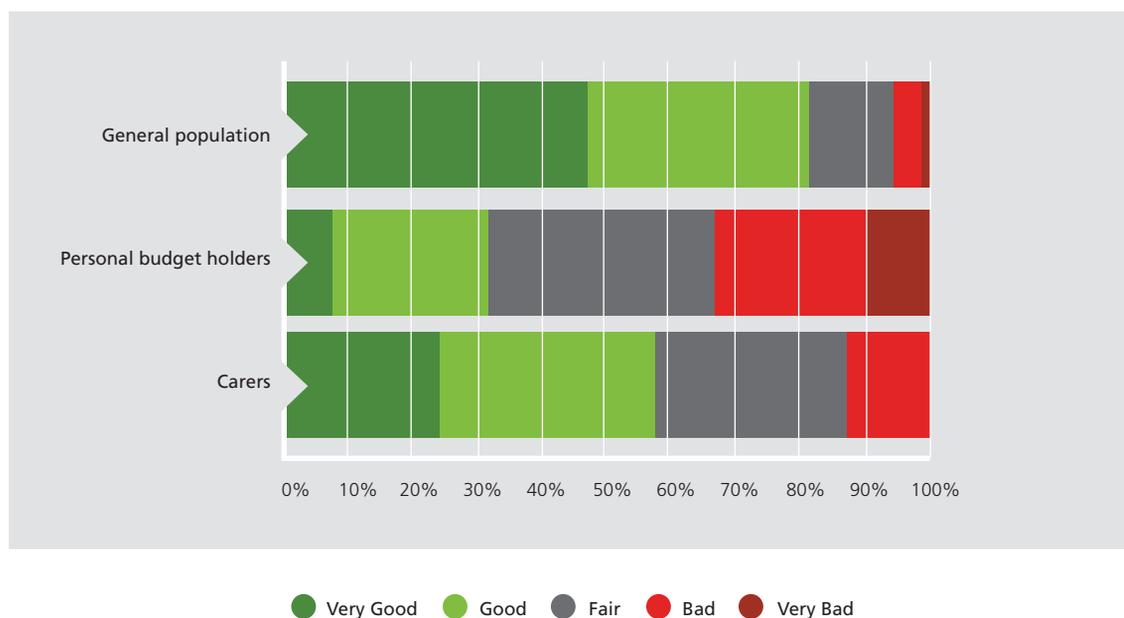
Equalities monitoring information for carers is presented in Appendix 2 of this report. In outline, this information shows:

- Most respondents (65.9%) were women.
- In terms of age, (8%) of carers were aged 18-44 years, 51.3 % were aged 45-64 years, and 40.7% were aged 65 years or over.
- Most respondents were White (93%).
- Most respondents were Christian (70.2%), with 17.7% reporting themselves to have no religion.

- Most respondents reported themselves to be heterosexual/straight (94.8%).
- A significant minority of carers (28.4%) reported themselves to have a disability or long-term health condition, most commonly a long-term health condition (17.3%).

We asked the same question used in the 2011 census concerning people’s self-rated general health in general to carers. As Figure 13 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 (57.5%) reported their health as good or very good, compared to less than a third (31.6%) of personal budget holders and more than three-quarters (81.4%) of the general population. The number of carers that reported their health as bad or very bad was 12.4%, compared to a third (32.8%) of personal budget holders and 5.4% of the general population.

FIGURE 13: Self-reported general health of carers vs personal budget holders’ vs the general population of England (Census 2011)



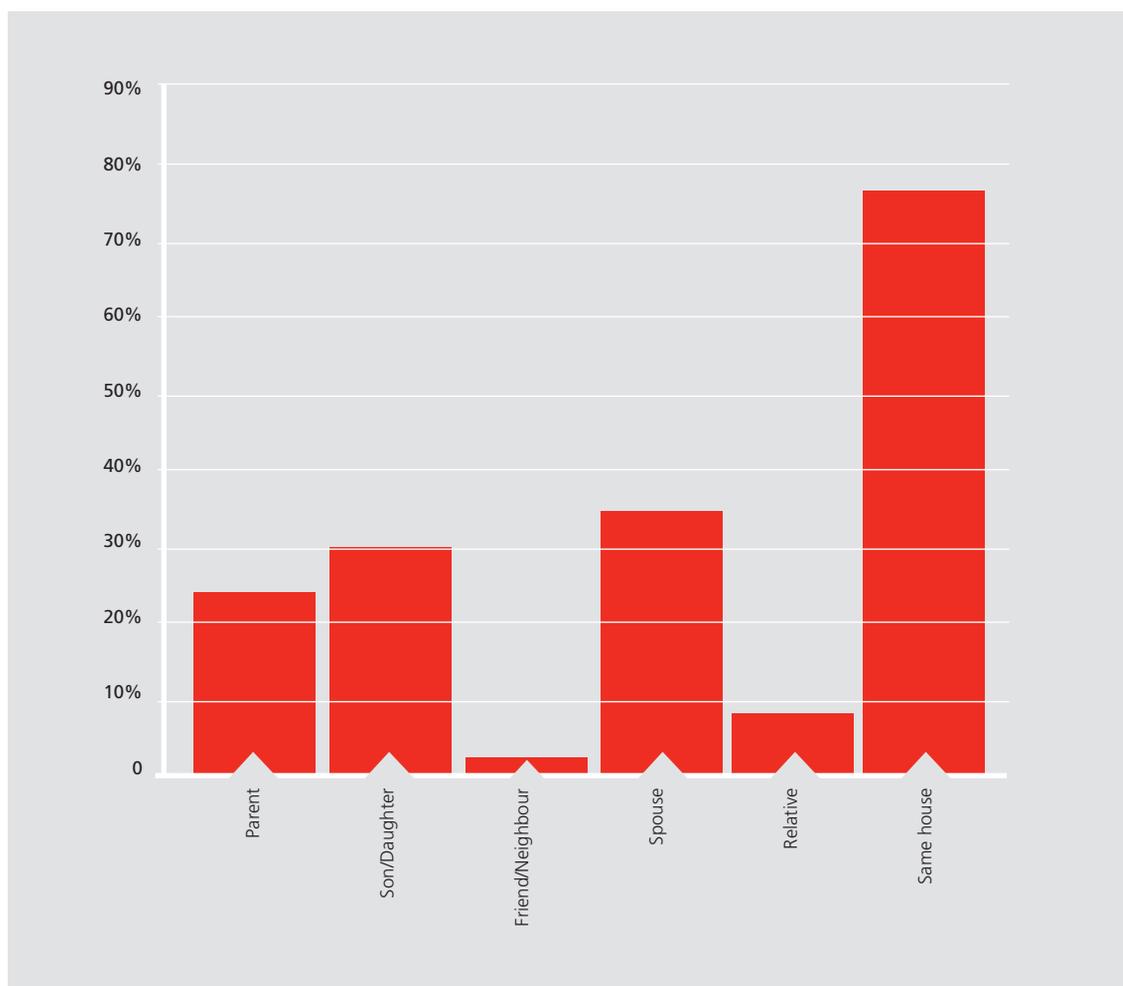
What are the circumstances of carers?

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

Figure 14 shows who carers in the POET survey were offering care and support to. Carers were most commonly caring for a partner/spouse (34.6%), followed by a grown-up son or daughter (30.6%) then an older family member (24.3%), with a small proportion of carers supporting someone else e.g. a friend or neighbour (2.3%), other relative (8.6%).

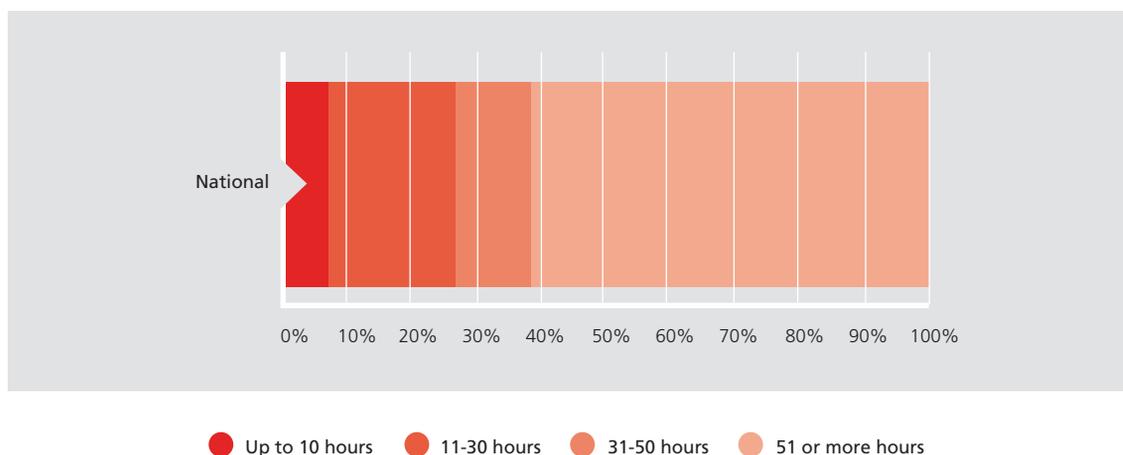
Figure 14 also shows that well over three quarters of carers (77.6%) were living in the same house as the person they were caring for.

FIGURE 14: Who carers give care and support to, and if carers live in the same house as the person cared for



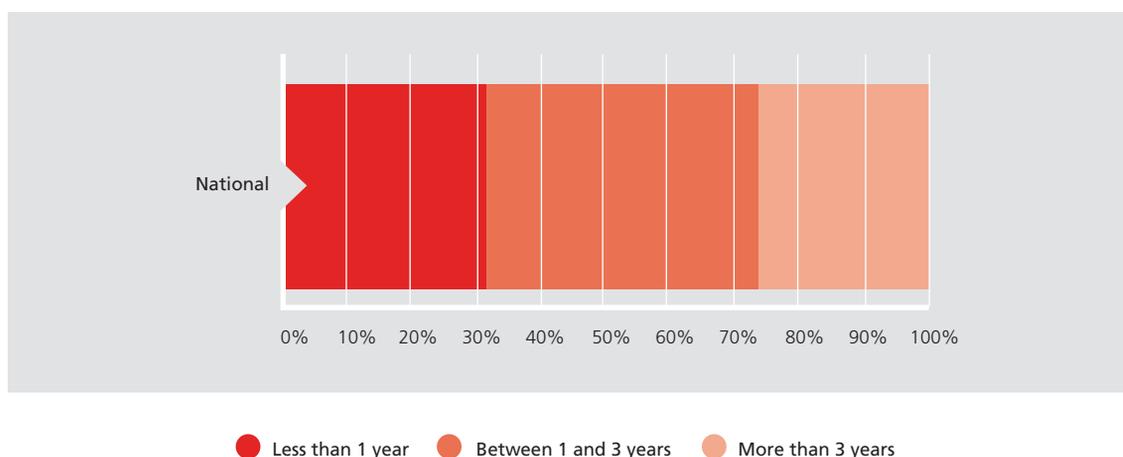
The POET survey also asked carers to estimate how many hours per week they would typically spend caring for the person they were supporting, responses are shown in four bands (up to 10 hours; 11-30 hours; 31-50 hours; and 51 or more hours). As Figure 15 shows, more than half of carers (62.3%) were caring for more than 50 hours per week.

FIGURE 15: Estimated hours per week spent caring



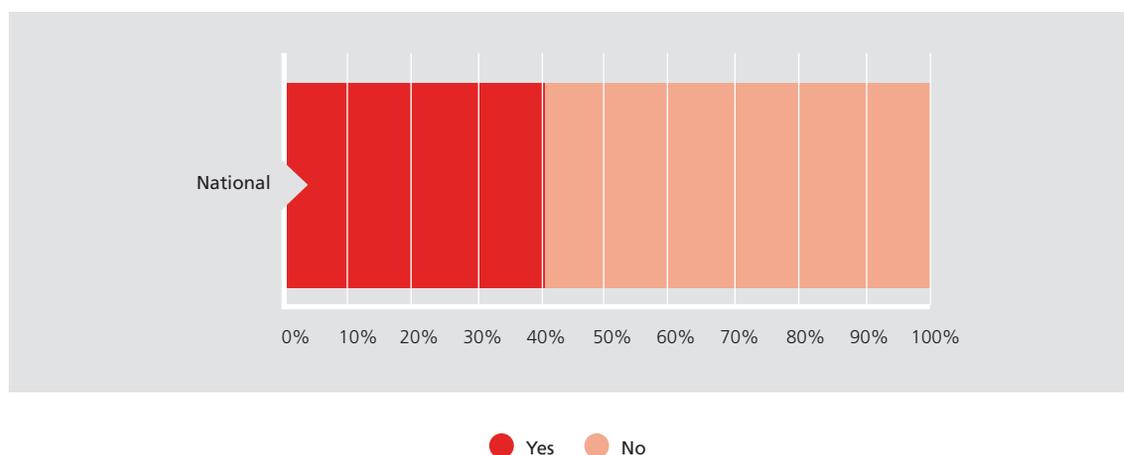
The POET survey asked carers how long the person they were caring for had been using a personal budget. Of the personal budget holders being supported by carers, 32.1% had had their personal budget for less than a year, 41% had had their personal budget between one and three years, and 26.9 % had had their personal budget for more than three years.

FIGURE 16: How long has the person you are caring for been using a personal budget?



Carers were asked whether the person being cared for had been receiving paid support before getting a personal budget. More than a third (39.7%) of the people being supported by carers had received paid care or support before their personal budget.

FIGURE 17: Did the personal budget holder get paid support before their budget?

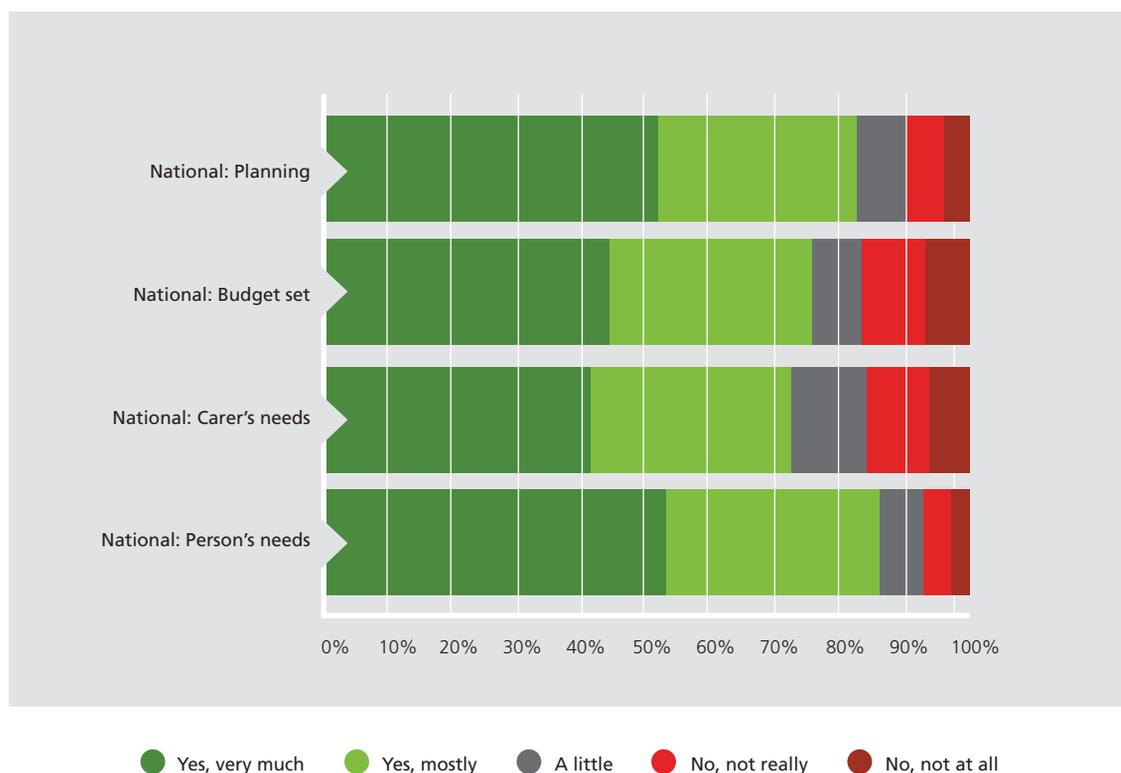


Carers' experience of the personal budget process

We asked carers questions about their experience of the personal budget process. We asked whether they 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 18 overleaf shows at least two thirds of carers (68.8%) 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 equally as likely to say their views had not been included when the budget was set (15.6%) and when their needs were assessed (15.5%).

FIGURE 18: Were carers' views included in the personal budget?



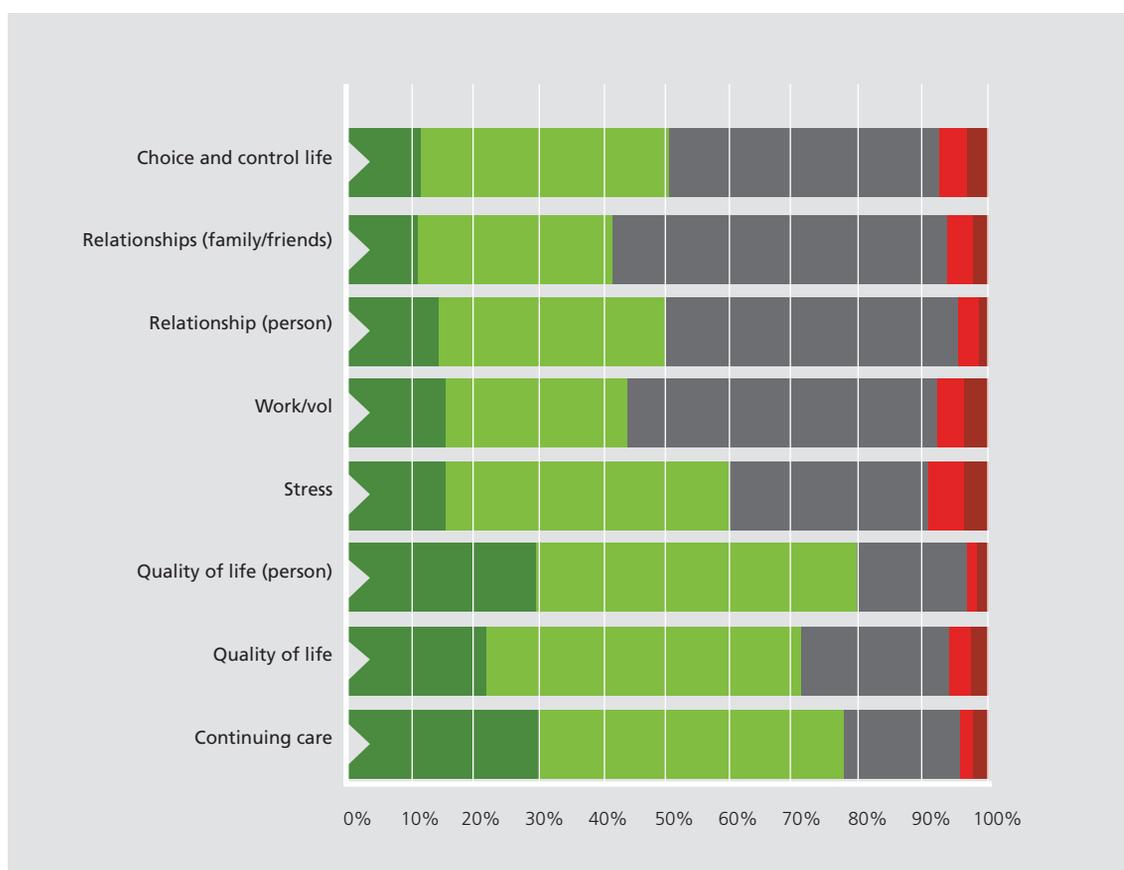
Have personal budgets made a difference to carers' lives?

The POET survey asks carers whether personal 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 19 opposite summarises the findings for carers. 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 two thirds of carers said that the person they care for having a personal budget had made things better or a lot better in three of the eight aspects we asked about: continue caring (78.6%); quality of life for the person being cared for (79.6%); and quality of life for the carer (71.3%).

Around half of carers said that the person they care for having a personal budget had made things better or a lot better in three of the eight aspects we asked about: day to day stress (60.6%); choice and control (51.1%); relationship with the person they care for (49.7%). Less than 9% of carers reported any areas of their lives getting worse as a result of personal budgets.

FIGURE 19: Outcomes for carers



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

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

Carers were asked to comment about their experience of having a personal budget. We asked carers what worked well, what didn't work well and what specific changes they would make. Figure 20 on page 62 shows that three quarters of carers commented on what had worked well (76.5%), more than half commented on what had not worked well (60.1%), and made a comment suggesting changes (61%).

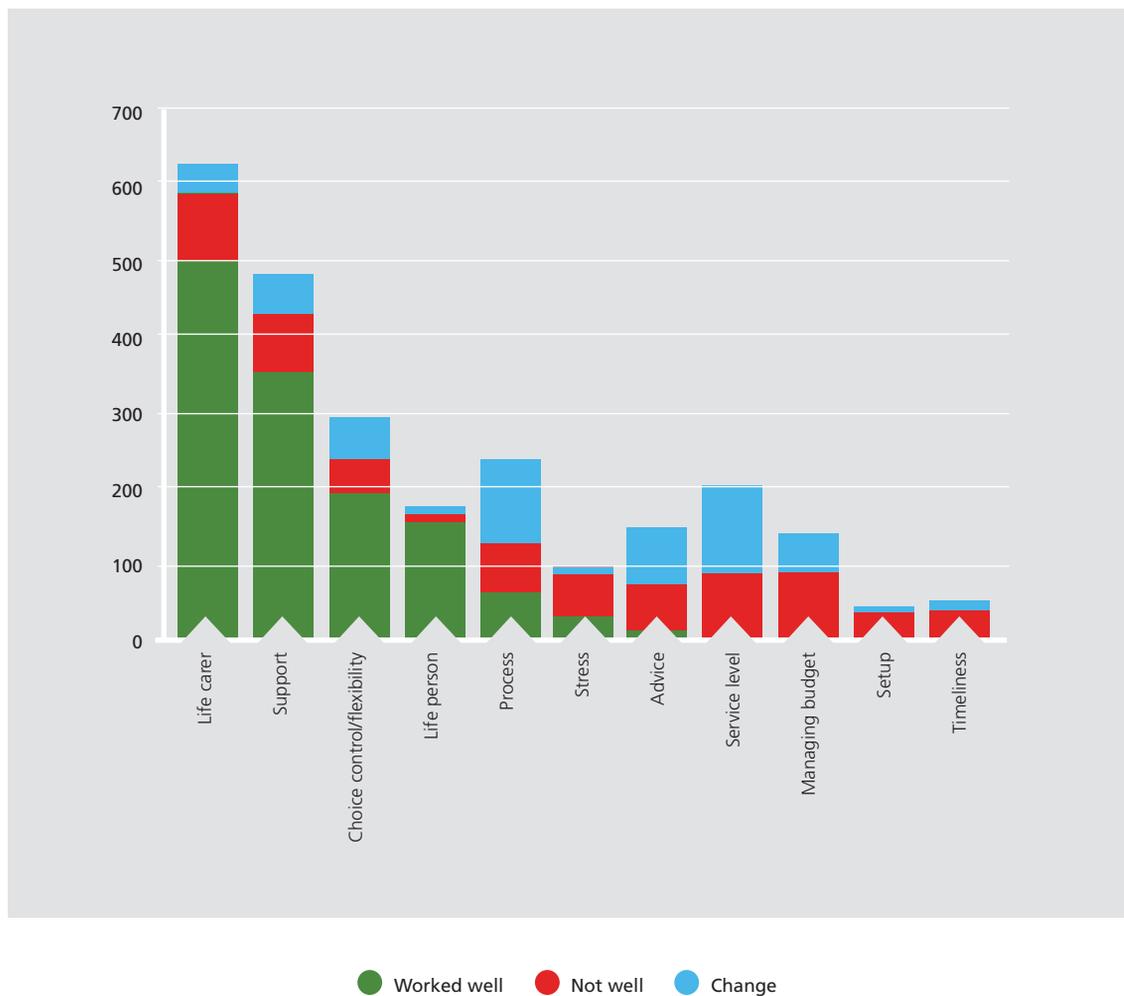
The length of response varied from a couple of words to several sentences, with most people providing just a single sentence. Responses tended to illustrate people's experience of the process of taking control of a personal budget or the impact the personal budget had on their life.

In addition to their experience of personal 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 budget and how important the support was to them. Where people made vague comments, these were not been assigned in the analysis presented here.

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 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 opposite summarise the issues and themes carers wrote about in response to the three free text questions.

Process	The experience of getting and controlling a budget. In particular the 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 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 budget.
Support	The quality, nature, range, impact, and availability of support as a result of having a personal budget including the degree of flexibility and choice.
Choice/control	The degree of choice and control the personal budget had allowed over treatment and support, and in other aspects of life.
Timeliness	The length of time taken to get the personal 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 budget on the role of the carer. Including the introduction of other paid carers and the demands of organising support and managing a personal budget.
Service level	The amount of money in the budget or service available as a result of having a budget

FIGURE 20: Carers of personal budget holders comments on what worked well, what didn't and what should change



What factors are associated with positive outcomes for carers?

Figure 19 on page 59 shows how carers feel the personal budget for the person they are supporting has affected (or not) eight areas of their lives as carers, and the life of the person they're supporting. In this section of the report we will ask four further questions:

- 1) Are there differences in the outcomes of personal budgets for carers depending on the carer's gender, ethnicity, self-reported disability or current health status?
- 2) Are aspects of the carer's situation (relationship to the person they're supporting; living in the same house as the person they're supporting; number of hours per week spent supporting the person) associated with positive outcomes?
- 3) Are aspects of the personal budget (organisation administering the personal budget; previous council support; length of time with personal budget; knowing the amount of the personal budget) associated with positive outcomes?
- 4) Are carers' perceptions of the processes involved in holding a personal budget (feeling that their views are included throughout the process; feeling that the council makes the personal budget process easy) 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 carers felt their views were fully included in budget setting, what the odds of them reporting a positive impact of their personal budget compared to if they had not felt included). An odds ratio of 1 would mean that a positive impact was no more or less likely if carers had felt fully included in setting the budget or not. An odds ratio significantly less than 1 would mean that a positive impact was less likely if carers had felt fully included. An odds ratio significantly more than 1 would mean that a positive impact was more likely if carers had felt fully included. 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 carers reporting the estimated amount of the personal budget, we did not conduct analyses of the relationship between the amount of the 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 when interpreting the results we report below.

It is also important to note that these analyses have only been conducted where people have rated the outcome indicator as relevant to them.

The tables opposite 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 and that cell is shaded green for a positive relationship and red for a negative relationship. All of these significant associations are reported in the text.

Table 8 below shows associations between personal factors of carers and positive impacts of the person's personal budgets on their carer.

The carer's gender and self-reported disability were not associated with any of the eight outcome indicators.

Carers from minority ethnic communities were more likely to report positive impacts of the person's budget on the carer's relationships with the person they support and other family and friends, and the amount of control the carer had over their own life.

Older carers were less likely to report a positive impact of the person's budget on the person's quality of life and on the opportunities for carers to engage in paid work or volunteering.

Carers who reported themselves as in good health were more likely to report a positive impact of the person's budget on the carer's quality of life and levels of stress, and on the opportunities for carers to engage in paid work or volunteering.

TABLE 8: Associations between carer personal factors and positive impacts of the person’s personal budget on the carer

Outcome	Factors potentially associated with outcomes: Personal factors of carers				
	Female gender	White	Older adult (aged 65 years+)	Self-reported disability	Fair/bad/ very bad self-rated health
Carer control over life	0.98	0.53*	0.91	0.84	0.79
Carer relationships with family/ friends	1.12	0.61*	0.82	0.93	0.91
Carer relationship with person being supported	0.97	0.48*	0.84	0.89	0.90
Carer opportunities paid work/ volunteering	1.12	0.68	0.53*	1.02	0.65*
Carer stress	1.13	0.87	0.83	0.91	0.73*
Quality of life: person being supported	1.06	0.66	0.57*	0.88	1.03
Quality of life: carer	1.28	0.89	0.84	0.79	0.72*
Continue caring	1.29	0.63	0.89	0.83	1.04

Table 9 opposite shows associations between the circumstances of carers and positive impacts of the person's personal budget on the carer.

Carers with different relationships with the person they are supporting reported different associations with outcomes.

Carers supporting a son or daughter were more likely to report a positive impact of their son/daughter's budget on: their son/daughter's quality of life; their relationship with their son/daughter; and their relationships with other family and friends. Carers supporting a partner or spouse were more likely to report a positive impact of their partner/spouse's budget on the carer's capacity to continue caring and the amount of control carers had over their own lives.

In contrast, carers supporting a parent were less likely to report a positive impact of their parent's budget on their relationships with other family and friends and the amount of control carers had over their own lives. In addition, carers supporting a friend or neighbour were less likely to report a positive impact of their friend/ neighbour's budget on the carer's capacity to continue caring and the carer's quality of life. Carers supporting an 'other' person were less likely to report positive impacts of the person's budget on six out of the eight outcome indicators.

Whether the carer lived in the same house as the person they were supporting was not associated with any outcome indicators, and carers reporting themselves as caring 24/7 were less likely to report a positive impact of the person's budget on the opportunities for carers to engage in paid work or volunteering.



TABLE 9: Associations between aspects of the circumstances of carers and positive impacts of the person's personal budgets on the carer

Outcome	Factors potentially associated with outcomes: The circumstances of carers						
	Caring for parent	Caring for son/ daughter	Caring for friend/ neighbour	Caring for partner/ spouse	Caring for other person	Living in same house as person being supported	Caring 24/7
Carer control over life	0.71*	1.18	0.82	1.32*	0.70	1.16	0.84
Carer relationships with family/ friends	0.72*	1.57*	1.30	1.01	0.51*	1.19	1.09
Carer relationships with person being supported	0.84	1.35*	1.01	1.13	0.50*	1.13	1.02
Carer opportunities paid work/ volunteering	1.09	0.90	0.63	0.94	1.17	0.83	0.55*
Carer stress	1.07	1.21	0.46	1.10	0.49*	1.11	0.86
Quality of life: person being supported	0.96	1.45*	0.69	1.10	0.46*	1.14	0.79
Quality of life: carer	1.03	1.23	0.43*	1.14	0.54*	1.16	0.99
Continue caring	1.01	1.02	0.31*	1.52*	0.50*	1.31	1.29

Table 10 opposite shows associations between various aspects of the personal budget and positive impacts of personal budgets on carers.

As Table 10 shows, the organisation funding the person's budget had few associations with outcomes for carers. Carers where the person had an NHS-funded budget were more likely to report a positive impact of the budget on the amount of control carers had over their lives. Carers where the person had a council-funded budget were more likely to report positive impacts of the budget on their capacity to continue caring and on the person's quality of life.

Similarly, where the person had had support before their budget, carers were more likely to report a positive impact of the budget on the person's quality of life.

Carers supporting people who had held their personal budget for a year or more were more likely to report positive impacts of the budget on the carer's opportunities to do paid work/volunteer and the carer's relationship with the person they're supporting. For those people who had held their budget for three years or more, carers were more likely to report positive impacts of the person's budget across all eight outcome indicators.

Carers who could report the amount of the person's budget were also more likely to report positive impacts of the budget across seven of the eight outcome indicators.



TABLE 10: Associations between aspects of the personal budget and positive impacts of the person's personal budgets on the carer

Outcome	Factors potentially associated with outcomes: The personal budget						
	NHS funding personal budget	Council funding personal budget	Both NHS and council funding personal budget	Council support before personal budget	Personal budget held for > 1 year	Personal budget held for > 3 years	Know amount of personal budget
Carer control over life	1.80*	0.88	1.10	1.22	1.09	1.36*	1.29*
Carer relationships with family/friends	1.26	1.08	1.15	1.16	1.18	1.51*	1.26
Carer relationships with person being supported	1.21	1.07	1.02	1.13	1.29*	1.49*	1.44*
Carer opportunities paid work/volunteering	1.48	1.02	1.09	1.05	1.41*	1.49*	1.50*
Carer stress	1.35	1.11	1.32	1.03	1.10	1.39*	1.35*
Quality of life: person being supported	0.97	1.48*	0.82	1.44*	1.19	1.43*	1.32*
Quality of life: carer	1.34	1.27	0.85	0.98	1.11	1.39*	1.90*
Continue caring	1.50	1.55*	0.69	0.83	1.18	1.45*	1.87*

Table 11 below shows associations between carers' perceptions of the personal budget process and positive impacts of the person's personal budget on their carer.

As Table 11 shows, when carers felt their views were included in all aspects of the personal budget process they were more likely to report positive impacts of the person's budget across all eight outcome indicators.

TABLE 11: Associations between carer perceptions of the personal budget process and positive impacts of personal budgets on carers

Outcome	Factors potentially associated with outcomes: Carers' views included in the process			
	Carer views included when person's needs assessed	Carer views included when carer's needs assessed	Carer views included when budget amount was set	Carer views included when support plan written
Carer control over life	3.09*	2.68*	2.09*	2.66*
Carer relationships with family/ friends	2.51*	2.21*	2.20*	2.86*
Carer relationships with person being supported	2.35*	1.94*	2.20*	2.43*
Carer opportunities paid work/ volunteering	2.04*	2.16*	1.94*	1.99*
Carer stress	4.05*	2.71*	2.42*	2.75*
Quality of life: person being supported	2.19*	1.49*	1.92*	2.25*
Quality of life: carer	4.56*	2.91*	2.83*	2.74*
Continue caring	4.51*	2.53*	2.53*	2.42*

Which factors are most strongly associated with positive outcomes of personal budgets for carers?

As Tables 8-11 make clear, many factors were associated with positive outcomes of personal budgets for carers. To explore which of these factors were most strongly associated with positive outcomes, we conducted a series of logistic regressions (one for each outcome indicator). These calculate which of all the factors listed in the tables above are statistically associated with the outcome indicator, while controlling for all the other factors potentially associated with that outcome indicator.

These analyses are exploratory, and it is important to bear the following issues in mind when interpreting the results. First, regressions are still associations – we cannot assume that the factor caused the positive outcome. Second, each regression requires a complete set of information for each person – because people could rate an outcome indicator as not relevant to them, their data could not be included in that regression equation. There was one outcome indicator (paid work/volunteering) where there were too few people for the regression to be robust, so regressions for these outcome indicators are not reported here. Finally, only factors with a strong association ($p < 0.01$) with the outcome indicator are reported in Table 12 overleaf.



Table 12 opposite shows some clear patterns in the factors most strongly associated with carers' perceptions of positive outcomes from the personal budget for the person they're supporting.

Personal factors or carers' circumstances were rarely strongly associated with outcomes for carers when other factors were taken into account (carers of working age were more likely to report a positive impact of the person's budget on the person's quality of life).

Certain aspects of the personal budget (for example which organisation funded the budget) were also rarely associated with outcomes for carers (carers where the person had an NHS-funded budget were more likely to report a positive impact of the person's budget on the carer's capacity to continue caring). Carers where the person had held a budget for three years or more were more likely report positive impacts of the person's budget on carer stress and carer relationships with other family and friends.

The factors most widely associated with positive outcomes all concerned the personal budget process. Carers who knew the amount of the person's budget were more likely to report positive impacts of the person's budget on carers' capacity to continue caring and carers' quality of life. Carers who felt their views were fully included when the person's needs were being assessed were more likely to report positive impacts of the person's budget on carers' capacity to continue caring, carers' quality of life and carers' stress. Carers who felt their views were fully included when the person's budget was set were more likely to report positive impacts of the person's budget on the quality of life of both the carer and the person holding the budget. Finally, carers who felt their views were fully included when their needs as carers were being assessed were more likely to report a positive impact of the person's budget on carers' control over their own lives.

TABLE 12: Logistic regressions: factors most strongly associated with positive outcomes

Factor	Corrected odds ratio (p)
Factors associated with positive impact of budget on carer control over life (n=712; Nagelkerke R²=0.17)	
Carer's views fully included in carer needs assessment	1.72 (p=0.007)
Factors associated with positive impact of budget on carer's relationships with other family and friends (n=701; Nagelkerke R²=0.16)	
Have had personal budget for 1+ year	1.75 (p=0.003)
Council/NHS made the personal budget easy	2.27 (p<0.001)
Budget spent on community/leisure	1.72 (p=0.001)
Budget spent on personal assistants	2.00 (p<0.001)
Factors associated with positive impact of budget on carer's relationship with the person they're supporting (n=730; Nagelkerke R²=0.15)	
No factors associated at p<0.01	
Factors associated with positive impact of budget on carer stress (n=740; Nagelkerke R²=0.18)	
Person has had budget for 3+ years	1.80 (p=0.005)
Carer's views fully included in person's needs assessment	2.45 (p=0.005)
Factors associated with positive impact of budget on the person's quality of life (n=745; Nagelkerke R²=0.13)	
Working age carer	2.10 (p=0.001)
Carer's views fully included in budget setting	1.98 (p=0.005)
Factors associated with positive impact of budget on the carer's quality of life (n=742; Nagelkerke R²=0.19)	
Carer knows amount of personal budget	1.63 (p=0.009)
Carer's views fully included in person's needs assessment	2.74 (p=0.002)
Carer's views fully included in budget setting	1.81 (p=0.008)
Factors associated with positive impact of budget on the carer's capacity to continue caring (n=744; Nagelkerke R²=0.22)	
NHS funded personal budget	7.41 (p=0.003)
Carer knows amount of personal budget	1.75 (p=0.007)
Carer's views fully included in person's needs assessment	3.55 (p<0.001)

8 CONCLUSIONS AND NEXT STEPS

We conclude from the latest National Personal Budget survey that personal budgets continue to be a positive development in policy and practice but that there is still quite a way to go before they realise their full potential. TLAP will continue to work with our partners and others to address the challenges of uneven delivery and the continuing experience of frustrating and unhelpful process. Over the next 12 months we will add to and share our understanding of what works best to deliver the very best results for people.

What will we do?

- Key findings from the National Personal Budget Survey will be shared in a range of workshops and events around the country, with people and family carers and their organisations, managers and practitioners. This will include the factors which are associated with best process and outcomes and examples of how to achieve these.
- Detailed analysis of the POET findings will be used to inform the practice guidance commissioned by TLAP and advice provided to the Association of Directors of Adult Social Care (ADASS).
- With support from the Department of Health the opportunity to use POET will continue to be offered to English councils.
- With our National Co-production Advisory Group we will explore the broadening of the survey to support feedback from people and families across additional areas of personalisation.
- We will work with ADASS to explore the possibility, in 2015, of the gathering of both council and personal budget holder/carer reported outcome information to provide a joined up picture of progress with personalisation to steer improvement efforts.

APPENDIX 1

EQUALITIES MONITORING INFORMATION FOR PERSONAL BUDGET HOLDERS RESPONDING TO POET

Ethnicity

2,385 personal budget holders provided information about their ethnic origin:

Ethnicity	
Any White	2,198
Mixed	40
Asian/Asian British	98
Black/ Black British	41
Chinese/Other	8



Religion

2,229 personal budget holders provided details of their religion:

Religion	
Buddhist	14
Christian	1,451
Hindu	8
Jewish	10
Muslim	70
Sikh	13
No religion	625
Any other religion	108

Sexuality

2,287 personal budget holders provided details about their sexuality:

Sexuality	
Heterosexual / straight	1,720
Gay, Lesbian Bisexual	62
Do not want to say	505

APPENDIX 2

EQUALITIES MONITORING INFORMATION FOR CARERS RESPONDING TO POET

Carers were asked to provide details about their age, gender, ethnicity religion and their sexuality. This information was used to check whether some groups were benefiting more from personal budgets than others.

Age

- 1,268 carers provided details of their age:
- 101 (8%) aged 18-44 years
- 651 (51.3 %) were aged 45-64 years
- 516 (40.7%) were aged 65 years or over

Gender

- 1,196 carers provided details of their gender:
- 789 (66%) were women
- 407 (34%) were men

Ethnicity

1,177 carers provided information about their ethnic origin:

Carer Ethnicity	
Any White	1099
Mixed	18
Asian/Asian British	42
Black/ Black British	13
Chinese/Other	5

Religion

1154 carers provided details of their religion:

Carer Religion	
Buddhist	3
Christian	810
Hindu	5
Jewish	14
Muslim	31
Any other religion	24
No religion	204
Do not want to say	64

Sexuality

1,076 carers provided details about their sexuality

Carers Sexuality	
Heterosexual / straight	1020
Gay or Lesbian	12
Bisexual	4
Other	40

APPENDIX 3

CHOICE AND CONTROL

At Leeds's May 2012 engagement session, it was recommended that a steering group should be established to develop recommendations for the improvement of the quality of personalised support locally. The group has been operating in Leeds since August 2013 and has made a significant contribution towards the development of the local 'Making it Real' action plan and in particular has been developing local information for personal budget holders about the process.

Leeds held a further POET survey in May 2014 and will be holding another workshop in October. This will set the agenda for the further work of the POET Steering Group as they move into the New Year.

LEEDS CASE STUDY: CHOICE AND CONTROL – A SHARED VISION

"My name is Lily Cheng. I was seriously injured in a 2009 motor accident. Fortunately, my intellect was not affected...though, some people might think unfortunately!

In June 2012, I was allocated a mixed package of agency carers & Direct Payment. I use the latter for Personal Assistants to mainly accompany me for outings, shopping...& meetings.

I attended the 1st Leeds Choice & Control Event in May 2013 from which the POET Steering Group was birthed.

Very early on, POET realised existing procedures & processes need to be known, including legal aspects, before any simplifications or improvements could be considered. Slowly but surely, POET is making progress on this issue. The beauty

of a steering group is that procedures could be broken down & 'chunks' assigned to relevant departments or organisations to feedback to the group.

POET meetings are open to all stakeholders & it is good to have a varied mix of attendees. The same people or organisations do not necessarily need to attend. Leeds is a large city with many people groups; POET can only work with the knowledge from its participants.

I believe that change can be good, but it must be considered, measured, monitored & evaluated to be accepted. The work of POET is a long term process, but there is willingness in those attending to work together for the benefit of Leeds service users."

– Lily Cheng – Personal budget holder and Leeds POET Steering Group Member

If you could choose one key aspect of making personalisation real in Leeds, what would it be?

Here are some of the comments received during the engagement session...



"Freedom and choice"

"Make personalisation more accessible for people with mental health problems"

"More information needed in public domain please! Re. What are personal budgets? What can they be used for? Payment options?"



**“More people
need to know”**



**“Different approach
to direct payments
– trusting people to
choose how to use
their funding”**



**“Help people to
understand more
and assist it any
way that I can”**

**“Make less paperwork
for SW and make
it easier for me to
manage my direct
payments – someone
to do employers part”**



Think Local Act Personal

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

web: www.thinklocalactpersonal.org.uk

email: thinklocalactpersonal@scie.org.uk

twitter: @tlap1

