



**Personal Health Budget/  
Integrated Personal Budget and  
Personal Wheelchair Budget  
Survey 2019**

**Results Summary**

## Contents

Introduction.....	3
Executive summary.....	4
Personal health budget/integrated personal budget questionnaire.....	4
Personal wheelchair budget questionnaire .....	5
Methodology and structure .....	5
Amendments to the 2019 questionnaires.....	7
Respondent details .....	8
Report context: the key features of a personalised and integrated approach to care .	9
Survey results .....	10
Key features findings .....	10
How people said they spent their budgets .....	21
Recommendation and quality.....	23
Managing personal assistants.....	27
Some key areas for improvement.....	30
Not able to choose preferred budget option.....	30
Unreasonable restrictions .....	31
Difficulty finding information.....	32
Other themes.....	32
Respondent details .....	33
Gender .....	33
Ethnicity.....	34
Disability.....	35
Sexual orientation.....	36
Geography .....	37
Age.....	38
Hearing from people about their suggestions for improvement.....	39
Next steps.....	41

## Introduction

A personal health budget is an amount of money to support someone's health and wellbeing needs, which is planned and agreed between them (or someone who represents them), and their local NHS team. It is not new money, but it may mean spending money differently so that a person can get the care that they need.

A personal health budget allows someone to manage their healthcare and support such as treatments, equipment and personal care, in a way that suits them.

A personal health budget can be managed in three ways or a combination of those.

- 1. Notional budget** - No money changes hands. You find out how much money is available for your assessed needs and together with your NHS team you decide on how to spend that money. They will then arrange the agreed care and support.
- 2. Third party budget** - An organisation legally independent of both you and the NHS (for example, an independent user trust or a voluntary organisation) holds the money for you, pays for and arranges the care and support agreed in your care plan.
- 3. Direct payment for healthcare** - You get the money to buy the care and support you and your NHS team agree you need. You must show what you have spent it on, but you, or your representative, buy and manage services yourself.

Thanks go to the personal health budget/integrated personal budget holders, the personal wheelchair budget holders, and their carers who responded to this survey.

This survey is part of a wider NHS England and NHS Improvement strategy to understand progress and hear people's experience of having a personal health budget/integrated personal budget and/or personal wheelchair budget. NHS England and NHS Improvement intends to use the findings from the survey to help shape national and local improvement activity.

This independent survey was commissioned by NHS England and NHS Improvement.

The 2019 personal health budget/integrated personal budget questionnaire was adapted from the [2018 survey](#), commissioned by NHS England and executed by Quality Health, and which was coproduced with people with lived experience of personal health budgets/integrated personal budgets. There were some small amendments made in the 2019 questionnaire, details of which can be found on [page 7](#) of this report.

The personal wheelchair budget questionnaire, new to the 2019 survey, was developed to mirror the personal health budget/integrated personal budget questionnaire where possible but also includes some distinct questions which are specific to personal wheelchair budget holders.

Quality Health implemented and analysed the [survey](#).

## Executive summary

This report summarises the results of the 2019 Personal Health Budget/Integrated Personal Budget and Personal Wheelchair Budget surveys, which aimed to understand people's experiences of getting and then having a personal health budget/integrated personal budget or personal wheelchair budget.

The survey was first executed in 2018 and was repeated in 2019 with some amendments. The results summary report from the 2018 survey is available on the [Quality Health website](#).

### Personal health budget/integrated personal budget questionnaire

Personal health budget/integrated personal budget survey respondents rated their experience of the **outcome** and what they have **achieved** by having a personal health budget/integrated personal budget at an average of **7.4** out of **10**. Their experience of **getting** a personal health budget/integrated personal budget was slightly lower, with an average rating of **6.0** out of **10**.

The survey highlighted an association between strength of positive experience and likelihood of recommendation, suggesting that quality is a key factor in achieving the [national ambition](#) for personal health budgets/integrated personal budgets.

People were overwhelmingly likely to recommend a personal health budget/integrated personal budget to somebody else, and a high proportion of people felt the care planning process worked well:

- **79%** of personal health budget/integrated personal budget survey respondents said they were extremely likely or likely to recommend a budget to someone else
- **85%** of personal health budget/integrated personal budget survey respondents said they were involved as much as they wanted to be in creating their personalised care and support plan, definitely or to some extent
- **89%** of personal health budget/integrated personal budget survey respondents said they had achieved what they wanted to as a result of their plan, to some extent or completely.

Respondents were asked how long they had had the budget for, and **25%** of respondents said they had had their personal health budget/integrated personal budget for less than a year. **82%** of these respondents said they were extremely likely or likely to recommend a budget to someone else. This is compared to **78%** of respondents who have their personal health budget/integrated personal budget for over a year.

Some of the findings have provided key areas for improvement:

- **18%** of personal health budget/integrated personal budget survey respondents said that they were not able to choose the option they wanted to manage the budget
- **27%** of personal health budget/integrated personal budget survey respondents said there were unreasonable restrictions on how they were allowed to spend their budget
- **42%** of personal health budget/integrated personal budget survey respondents said that it was quite difficult or very difficult to find more information about personal health budgets/integrated personal budgets.

Though the survey methodology precludes direct year on year comparisons, the figures are broadly similar to those in the 2018 survey results summary report.

## Personal wheelchair budget questionnaire

Personal Wheelchair Budgets are still very new and as such, the number of responses to this questionnaire was very low. Therefore, that data is not included in the figures above and cannot be analysed further. The remainder of this report focuses on the personal health budget/integrated personal budget survey results.

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‘I think they're potentially transformational for both patient and carer, and the only improvement I can think of is that they should be made available to more people, and their availability should be made much more widely known.’

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## Methodology and structure

As per the 2018 survey, the 2019 survey was also run online, with respondents self-selecting and consenting to take part. Participants were sought from as wide a range of backgrounds and geographies as possible – with the survey being publicised through networks of patient, provider, and support organisations, other groups, some CCGs, newsletters and social media.

In 2019, additionally printed and printable questionnaires were made available, to allow for offline completion and return by post. 4 postal returns were received in total.

Responses for the survey was gathered between 14 March and 31 May 2019.

A freephone helpline was available for respondents to ask questions about the survey, to enable them to complete their questionnaire over the phone or request a printed questionnaire, and to provide access to a translation and interpreting facility for those whose first language was not English – no one used this facility however.

The personal health budget/integrated personal budget questionnaire had 67 questions; the personal wheelchair budget questionnaire had 51 questions.

The questions covered:

1. Respondent details
2. Finding out about budgets
3. Getting clear information
4. Understanding your health and well-being needs
5. Working out how much money is available
6. Creating a personalised care and support plan
7. Organising your care and support
8. Managing your own staff\*
9. Monitoring and review\*
10. Your overall experience
11. Demographic and related information

\* Personal health budget/integrated personal budget questionnaire only

Questions were primarily multiple choice – but the survey also invited respondents to provide written answers for some questions. Though the extensive qualitative feedback is not covered in detail in this report, it will be used by NHS England and NHS Improvement alongside the quantitative data to inform improvement activity.

## Amendments to the 2019 questionnaires

In the personal health budget/integrated personal budget questionnaire, there were seven new questions, and two questions which had a small change to the wording. Three questions were removed. All of the other questions remained the same as the 2018 questionnaire.

The new questions added were:

- Do you also have a personal wheelchair budget?
- If you currently have a personal health budget/integrated personal budget, how long have you had it for?
- If you used to have a personal health budget/integrated personal budget in the past but no longer have one, when did it end?
- If you would like to tell us more about why you chose the [budget] option you did, please tell us here.
- We are interested to understand how people are using their personal health budgets/integrated personal budgets. If you would like to tell us more about how you spent the budget and why, please tell us here.
- If you have accessed training for delegated healthcare tasks for your own staff, who provided the training?
- If you would like to make any other comments about your experience of using a personal health budget/integrated personal budget, please do so in the box below and overleaf.

The personal health budget/integrated personal budget questionnaire is available to read online on the [Quality Health website](#).

The personal wheelchair budget questionnaire was new this year, but as many questions as possible were retained and/or adapted from the 2018 personal health budget/integrated personal budget survey for consistency. A number of the 2018 questions were removed as they were not applicable, and three new questions were added with one being specific to personal wheelchair budgets.

## Respondent details

There were **419** responses to the personal health budget/integrated personal budget survey in total. This is an increase over the number of responses received to the 2018 survey, which was 390.

**141 (34%)** of these were filled in directly by the person that the questionnaire related to. The remaining **278 (66%)** questionnaires were filled in on their behalf by somebody else. Of these **103 (38%)** were filled out by a relative/friend, **88 (33%)** by a parent carer, **54 (20%)** by a family carer. The remaining **24 (9%)** consisted of health care professionals, paid carers and 'other'.

**384 (92%)** respondents currently had a personal health budget/integrated personal budget, and another **11 (3%)** had had one in the past. Of those respondents, **18 (4%)** also had a personal wheelchair budget, and a further **14 (3%)** had had one in the past.

Of those who currently had a personal health budget/integrated personal budget, **97 (25%)** had had one for less than a year; **140 (36%)** had had one for between 1 and 3 years; **92 (23%)** had had one for between 3 and 5 years; and **65 (16%)** had had one for more than five years.

Respondents were asked about the options they had used to manage their personal health budget/integrated personal budget, with the following response numbers:

- **243 (58%)** respondents said that they had used a direct payment held by them, a family member or friend
- **97 (23%)** respondents said that they had used a direct payment held by someone else on their behalf
- **56 (13%)** respondents said that they used a third party budget held by a provider organisation (sometimes known as an individual service fund)
- **41 (10%)** respondents said that they used a notional budget held by the council or NHS
- **32 (8%)** respondents said that they used a pre-paid card
- **6 (1%)** respondents said they had used another option to manage it.\*

\*Some respondents had a mix of options they used to manage their personal health budget, so the percentages will not equal 100%.



## Report context: the key features of a personalised and integrated approach to care

A series of key features have been co-produced with people with lived experience of personal health budgets. To be able to count as a personal health budget, the six key features in bold below need to be in place. They describe what a person should expect to experience from the process of getting and then having a personal health budget, and have been used in the following section to contextualise the findings from this survey.

For people to have a personalised and integrated approach to care a person should<sup>1</sup>:

- **Be able to access information and advice that is clear and timely and meets their individual information needs and preferences**
- **Experience a coordinated approach that is transparent and empowering**
- **Have access to a range of peer support options and community based resources to help build knowledge, skills and confidence to manage their health and wellbeing**
- **Be valued as an active participant in conversations and decisions about their health and wellbeing**
- **Be central in developing their personalised care and support plan and agree who is involved**
- **Be able to agree the health and wellbeing outcomes\* they want to achieve, in dialogue with the relevant health, education and social care professionals.**

If this leads to a personal health budget, a person should:

- **Know upfront an indication of how much money they have available for healthcare and support**
- **Have enough money in their budget to meet the health and wellbeing needs and outcomes\* agreed in the personalised care and support plan**
- **Have an option to manage the money as a direct payment, a notional budget, a third party budget or a mix of these approaches**
- **Be able to use the money to meet their outcomes in ways and at times that make sense to them, as agreed in their personalised care and support plan.**

**\*and learning outcomes in the case of children and young people**

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<sup>1</sup> Visit the link to see the full PDF

<https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/personal-health-budget-phb#guidance>

## Survey results

This section looks at a selection of the survey questions relating to the personal health budget key features in the previous section.

### Key features findings

**Key feature: Be able to access information and advice that is clear and timely and meets their individual information needs and preferences.**

A number of questions in the survey asked about respondents' experiences of the information, advice and support provided.

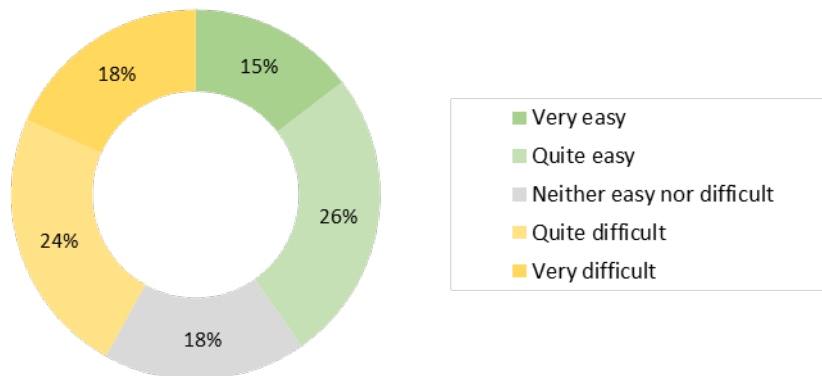
Themes coming out of the free text comments suggest that information continues to be one of the key areas of concern for budget holders.

**Q8: How did you first hear about personal health budgets/integrated personal budgets?**

From my healthcare professional	33%
From Social Services	28%
I found out for myself – online	9%
From a voluntary organisation/charity	6%
From family/friends	6%
From another personal health budget/integrated personal budget holder	3%
From my GP	2%
I found out for myself – printed information/leaflet	1%
Other	9%
Don't know/can't remember	2%

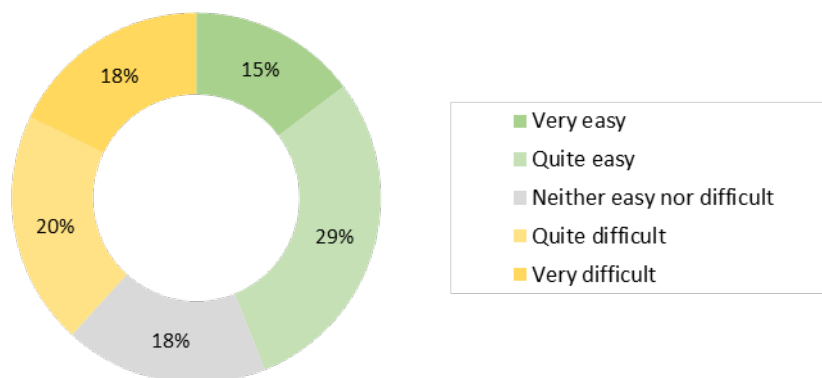
**40%\*** of respondents said that it was very or quite easy to find more information about personal health budgets/integrated personal budgets in their area, once they decided they wanted it (highlighted in the graph below).

**Q9. Once you decided you wanted more information about personal health budgets/integrated personal budgets in your area, how easy was this to find?**



**44%** of respondents said that it was very or quite easy to make contact with someone who could tell them more about personal health budgets/integrated personal budgets.

**Q10. How easy was it to make contact with someone who could tell you more about personal health budgets/integrated personal budgets?**




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**'I think that the biggest challenge is that there are too few staff members for the amount of work to be done, therefore, they often cannot provide a timely response.'**

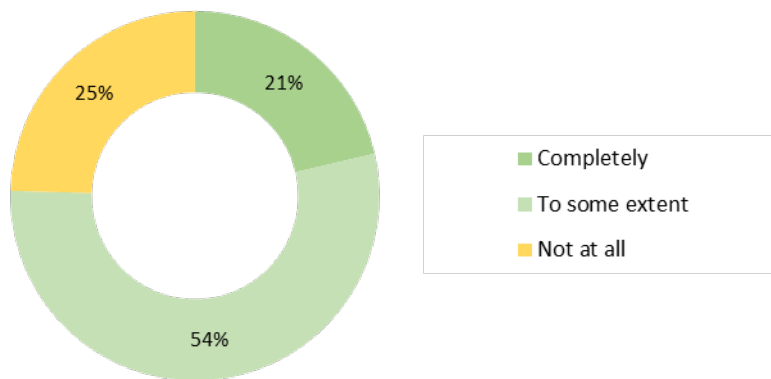
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\*This is a combination of results and has been rounded down to the nearest percentage. The figures in the chart have been rounded up and therefore do not match exactly.

**56%** of respondents said that they were given enough information about personal health budgets/integrated personal budgets.

**21%** answered 'completely' when asked if they had received useful information, at the time they needed it, to help them manage their health and well-being.

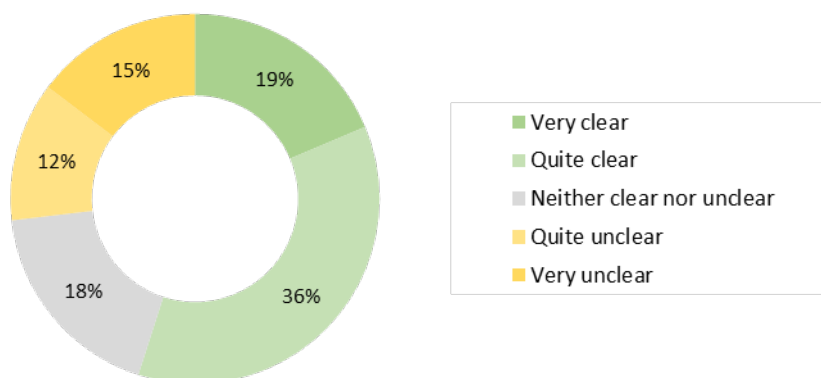
**Q12. To what extent do you receive useful information, at the time you need it, to help you manage your health and wellbeing?**



This was followed by a multiple selection question asking how the information they received was provided. **65%** of respondents said that they received the information 'verbally, face-to-face'; followed by **45%** saying 'over the phone'; and **39%** said 'via email'.

**55%** of people said that the information they received about personal health budgets/integrated personal budgets was very or quite clear.

**Q14. How clear was the information you were given about personal health budgets/integrated personal budgets?**



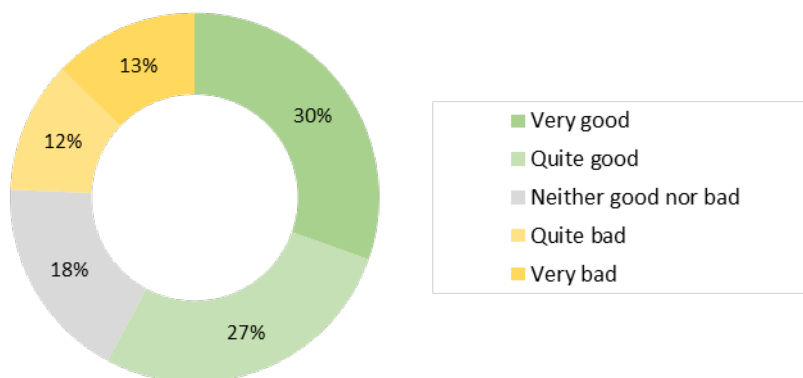
Most of the respondents (**69%**) were given information on direct payments held by themselves, a family member or friend. Fewer were given information on third party budgets held by a provider organisation (**24%**) or notional budgets held by the council or NHS (**19%**).

**Q29: Which of the following options for managing a personal health budget/integrated personal budget were you given information on? (multiple selection question)**

Direct payment held by me, a family member or friend	<b>69%</b>
Direct payment held by someone else on my behalf	<b>41%</b>
Third party budget held by a provider organisation	<b>24%</b>
Notional budget held by the council or NHS	<b>19%</b>
Pre-paid card	<b>10%</b>
Other	<b>2%</b>
Don't know	<b>4%</b>
Not applicable	<b>2%</b>

**58%\*** of respondents said the support they received on managing their personal health budget/integrated personal budget was very or quite good.

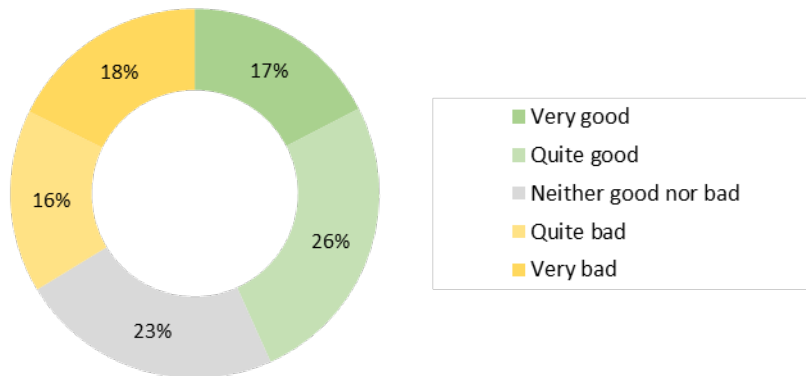
**Q35. In your opinion, how good was the support you received on managing your personal health budget/integrated personal budget?**



\*This is a combination of results and has been rounded up to the nearest percentage. The figures in the chart have been rounded down and therefore do not match exactly.

**43%** of respondents said the signposting/support they received to find the right suppliers, providers, products or personal assistants to put their care and support plan into action was very or quite good.

**Q36. In your opinion, how good was the signposting/support you received to find the right suppliers, providers, products or personal assistants to put your care and support plan into action?**



**Key feature: Be valued as an active participant in conversations and decisions about their health and wellbeing**

**87%** of respondents said that they thought their health needs were understood, absolutely or to some extent.

**81%** of respondents said that they thought their well-being needs were understood, absolutely or to some extent.

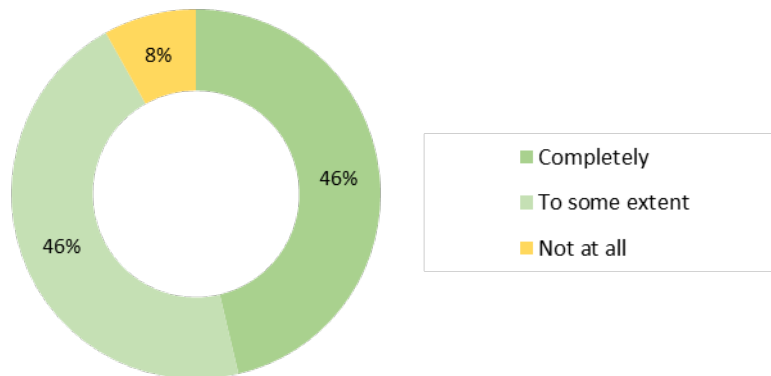
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‘Staff always extremely supportive and willing to help.’

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**92%** of respondents said that they felt they had been involved in the assessment of their health and well-being needs, completely or to some extent.

**Q18. To what extent do you feel you have been involved in the assessment of your health and well-being needs? (If you are no longer receiving a personal health budget/integrated personal budget, please think about the time that you were)**



**90%** of respondents said they felt their health and well-being needs had been reflected in their personal health budget/integrated personal budget, completely or to some extent.

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‘The plan was very formulaic and quite rigid, and does not have much flexibility to allow for any future changes without a long and complicated review.’

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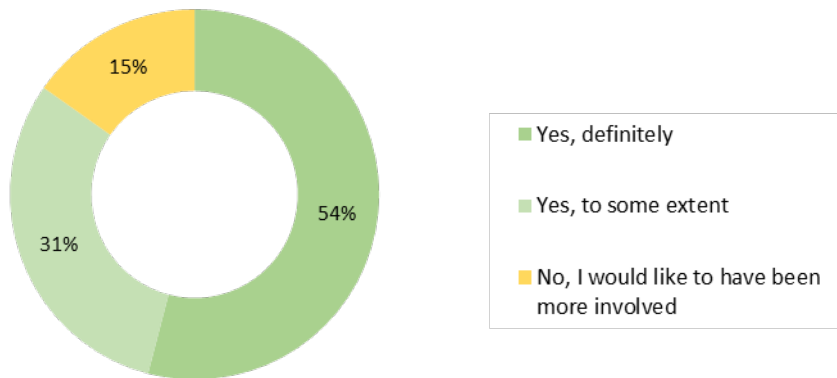
‘The difference a personalised conversation made was huge. More time given to understand what a budget was and how it could be used and managed. Totally done at our pace.’

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**Key feature: Be central in developing their personalised care and support plan and agree who is involved**

**85%** of respondents said that they were definitely or to some extent involved as much as they wanted to be in creating their personalised care and support plan.

**Q25. Were you involved as much as you wanted to be in creating your personalised care and support plan?**



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‘[Creating a personalised care and support plan...] was the most difficult part of the process. However, it’s the most important part of your personal health budget. Clear support plans create a framework which makes it easier to train carers.’

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‘I wrote most of the personalised care plan, so the professionals were completely aware of what we needed for my relative and what issues were important/relevant.’

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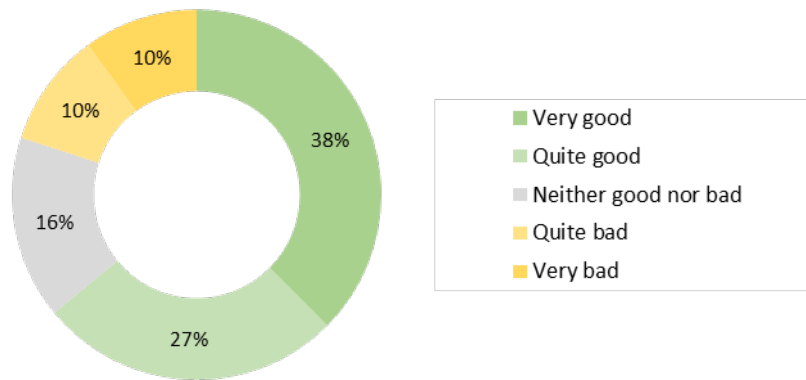
‘In reality I wasn’t involved at all [in creating my own personalised care and support plan], I was asked for information but it wasn’t taken into account the same way the professionals information was...’

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**64%** of respondents said that the support they received to develop their personalised care and support plan was very or quite good.

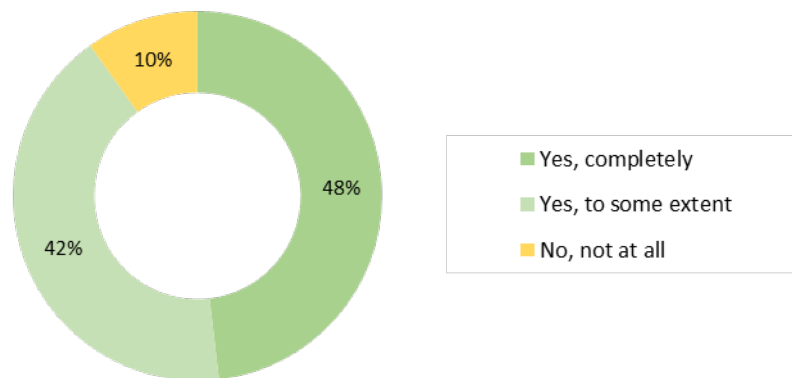
**Q27. In your opinion, how good was the support you received to develop your personalised care and support plan?**



**Key feature: Be able to agree the health and wellbeing outcomes they want to achieve, in dialogue with the relevant health, education and social care professionals**

**90%** of respondents said that their plan reflected what matters to them, completely or to some extent.

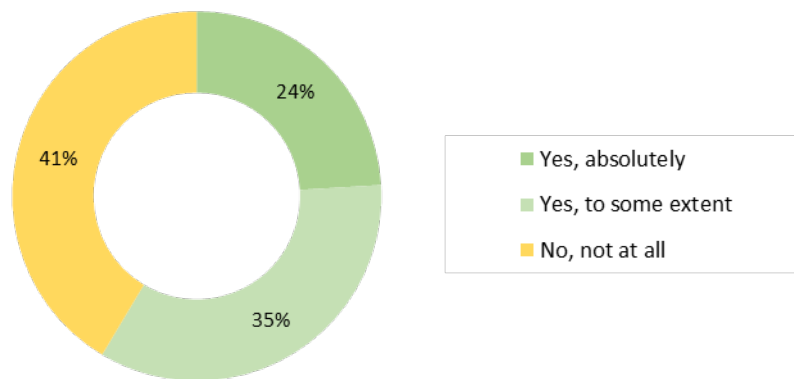
**Q26. In your opinion, how well does/did your plan reflect what matters to you?**



**Key feature: Know upfront an indication of how much money they have available for healthcare and support**

**59%** of respondents said that they understood at the start of the process how much money would be available in their personal health budget/integrated personal budget, absolutely or to some extent.

**Q20. Did you understand at the start of the process how much money would be available in your personal health budget/integrated personal budget?**

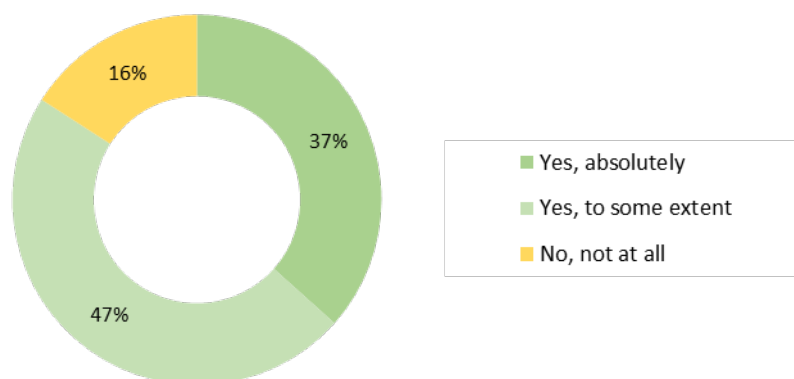


**64%** of respondents said they understood the process for deciding the amount of money available, absolutely or to some extent.

**Key feature: Have enough money in their budget to meet the health and wellbeing needs and outcomes agreed in the personalised care and support plan**

**84%** of respondents said that the money available in their budget is/was sufficient for their identified needs, absolutely or to some extent.

**Q23. In your opinion, is/was this sufficient money for your identified needs?**



**Key feature: Have the option to manage the money as a direct payment, a notional budget, a third party budget or a mix of these approaches**

**Q30: Which of the following options have you used for managing a personal health budget/integrated personal budget? (multiple selection question)**

Direct payment held by me, a family member or friend	<b>58%</b>
Direct payment held by someone else on my behalf	<b>23%</b>
Third party budget held by a provider organisation	<b>13%</b>
Notional budget held by the council or NHS	<b>10%</b>
Pre-paid card	<b>8%</b>
Other	<b>1%</b>
Don't know	<b>3%</b>
Not applicable	<b>2%</b>

**9%** of respondents who answered this question selected 'I was not given any of the options above'.

**82%** said that they were able to choose the option they wanted for managing their personal health budget/integrated personal budget.

When asked which options they had been given information on, however, it is clear that respondents were not given information on all options (see Q29 earlier in this report) and this was a similar picture in the 2018 survey.

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'Very difficult to get concrete information on exactly how much the budget was and how it could be spent. Lots of vague answers and professionals who were very unclear. It took a very long time to get proper information and it is still not easily understood.'

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'Everybody involved agreed on the amount of money that was needed, but it was refused because there is an upper limit and it doesn't matter what the actual needs are, that is the most available and we'll have to make do with it.'

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'The PHB amount hasn't changed since being awarded, this hasn't kept up with wage rises in other jobs and it's now very hard to attract care workers.'

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**Key feature: Be able to use the money to meet their outcomes in ways and at times that make sense to them, as agreed in their personalised care and support plan**

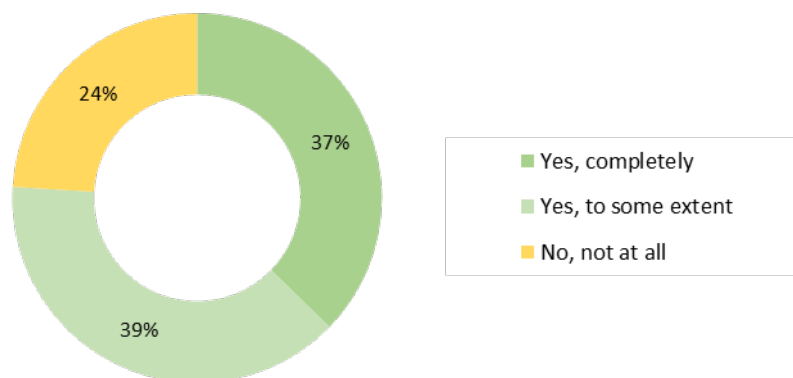
**73%** of respondents said that there were no restrictions on how they were allowed to spend their personal health budget/integrated personal budget (for example, only being able to use one supplier or having a limit placed on how much money they could withdraw); or that there were restrictions, but they seemed reasonable.

**Q33: Are/were there any restrictions on how you are/were allowed to spend your personal health budget/integrated personal budget?**

Yes, but they seem/seemed reasonable to me	<b>49%</b>
Yes, and they seem/seemed unreasonable to me	<b>27%</b>
No	<b>25%</b>

**76%** of respondents said that they had enough flexibility to spend different amounts of money in different months, either completely or to some extent.

**Q34. Do/did you have enough flexibility to spend different amounts of money in different months?**



**82%** of respondents said that they understood what the money could be spent on, absolutely or to some extent.

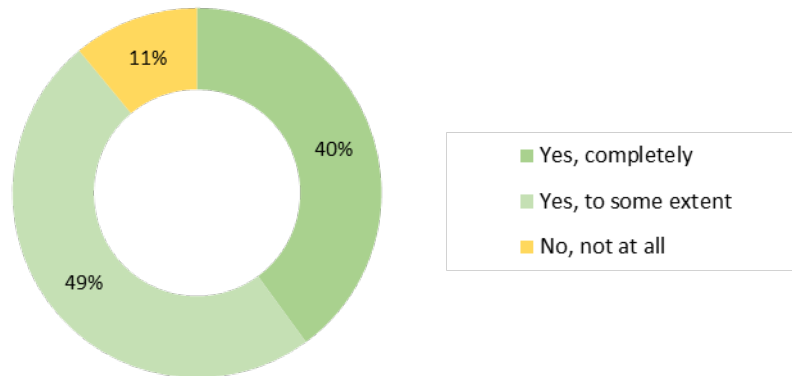
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‘The flexibility of the scheme makes arranging for my complex and dynamic medical needs to be cared for far easier. I use a service to handle all of the employment obligations, so the system is basically very fit for purpose.’

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**89%** of respondents said that they had achieved what they wanted to as a result of their plan, completely or to some extent.

**Q56. Have you achieved what you wanted to as a result of your plan?**



### How people said they spent their budgets

In the survey we asked respondents how they spent their personal health budget/integrated personal budget money and why.

The majority of respondents who provided feedback to this free text question spent their budget on personal assistants and/or carers, and costs associated with this provision; sometimes this was direct employment and other times via an agency. Money was also spent on costs associated with respite care.

Some respondents felt they had unfair restrictions on their budget, for example they were told they could only spend it on care, or spending their budget on anything other than care was not discussed at all. Some respondents noted that flexibility they had previously had was being removed. Where the budget was insufficient or insufficiently flexible, respondents were sometimes funding the additional items or services themselves (including out of their benefits).

Where respondents felt they had a budget that met their health and well-being needs, in addition to spending money on personal assistants/carers, they spent the money on a range of other items, such as therapies (e.g. hydrotherapy, physiotherapy, massage therapy), products and consumables, equipment (e.g. foldable ramps), and fitness or social activities (e.g. gym membership, National Trust membership).

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*'I was given information about how PHB's worked in terms of how the funding worked and how I could manage the money, but not so much about different ways I could actually use the PHB to meet my individual needs in a more personalised and creative way. The information given was generic and not personalised to meet my individual needs.'*

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Respondents further gave detail that made it clear that it was not simply the item or service being purchased that made the difference for them, but the ability to tailor the purchase in exactly the way that fitted with their lives, and the lives of their family members.

The reasons respondents gave for how the budget was spent were similar – to maximise independence of the budget holder, reduce pain and reduce unnecessary time in hospital, and support them to lead a socially active and fulfilling life. The transformative impact of a genuinely personalised budget was also felt by the family – relief that their family member was as independent as possible and well cared for, and more time and energy to engage in their own lives.

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‘The budget allows us to tailor the care our child gets to suit their ability, disability and general day to day needs. It is without a doubt brilliant!’

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‘Our budget manager was superb! Totally focused on what we wanted rather than prescribing what was available. Has totally changed our lives.’

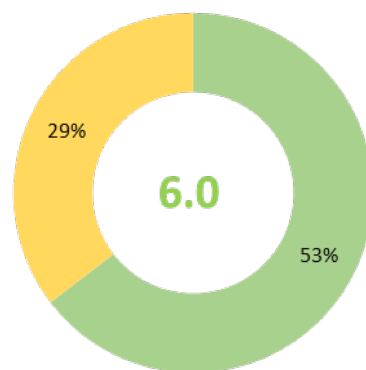
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## Recommendation and quality

Questions 55 to 60 asked respondents about their overall experience of getting and having a personal health budget/integrated personal budget.

**Finding: Respondents rated the experience of having a personal health budget/integrated personal budget higher than the experience of the process of obtaining a personal health budget/integrated personal budget.**

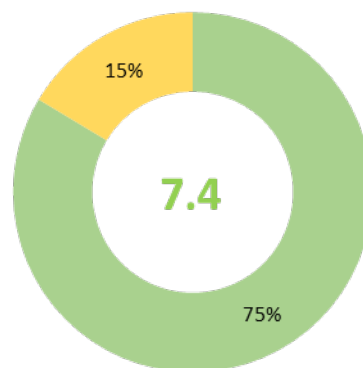
**Q58. How would you rate the overall experience of the process of getting a personal health budget/integrated personal budget/on a scale of 1 to 10? (Where 1 is very poor and 10 is excellent.)**



\*Number in the middle of chart is the average score between 1-10.

■ 7 or higher ■ 4 or lower

**Q59. How would you rate your overall experience of the outcome and what you have achieved by having a personal health budget/integrated personal budget on a scale of 1 to 10? (Where 1 is very poor and 10 is excellent.)**

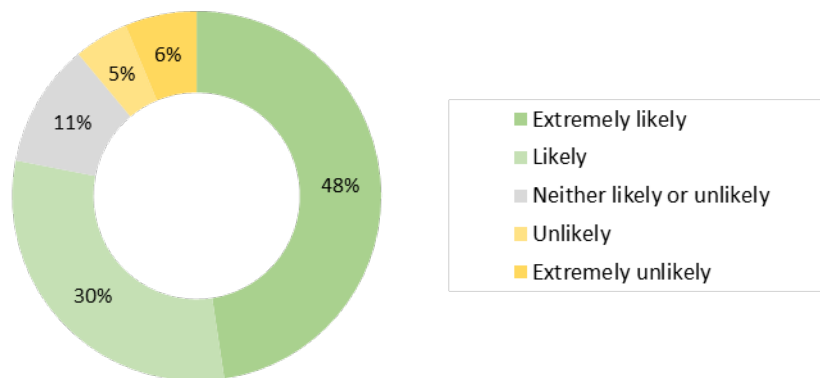


\*Number in the middle of chart is the average score between 1-10.

■ 7 or higher ■ 4 or lower

**Finding: Respondents who rated getting/having a personal health budget/integrated personal budget more highly were more likely to recommend one to someone else**

**Q60. How likely would you be to recommend a personal health budget/integrated personal budget to someone else?**



Looking at the relationship between Q58 and Q59, and whether the budget holder would go on to recommend a personal health budget/integrated personal budget in Q60:

- Of the **217** respondents who rated the process of getting a personal health budget/integrated personal budget as 7 or higher, **138** were extremely likely to recommend one and **62** were likely to recommend one (only **3** said they were unlikely or extremely unlikely to recommend).
- Of the **306** respondents who rated the outcome and achievements of having a personal health budget/integrated personal budget as 7 or higher, **179** were extremely likely to recommend one and a further **99** were likely to recommend one (only **5** said they were unlikely or extremely unlikely to recommend).

These results mirror those of the 2018 survey and as such, suggest again that there may be an association between the two questions in each pair, indicating that using the question 'How likely would you be to recommend a personal health budget/integrated personal budget to someone else?' as a measure of quality is reasonable.



**Finding: Respondents who rated certain key aspects of the process more positively were more likely to recommend a personal health budget/integrated personal budget to someone else**

We looked at how the strength of the positive experience of certain key aspects of the process relates to how respondents answered the question ‘How likely would you be to recommend a personal health budget/integrated personal budget to someone else?’.

Percentages shown are respondents who answered the question as per the column heading and went on to say they were ‘Extremely likely’ or ‘Likely’ to recommend a personal health budget/integrated personal budget to someone else.

**Table: the percentage of respondents who were extremely likely or likely to recommend a personal health budget/integrated personal budget, split by strength of positive response to a subset of questions**

Question	Yes, absolutely or Yes, completely or Yes, definitely	Yes, to some extent
Did you understand at the start of the process how much money would be available in your personal health budget/integrated personal budget?	90%	80%
In your opinion, is / was this sufficient money for your identified needs?	94%	80%
Were you involved as much as you wanted to be in creating your personalised care and support plan?	89%	75%
In your opinion, how well does / did your plan reflect what matters to you?	93%	75%
Do / did you have enough flexibility to spend different amounts of money in different months?	93%	85%
Have you achieved what you wanted to as a result of your plan?	96%	77%

Similarly, the table below shows the relationship between being able to choose the personal health budget/integrated personal budget option they wanted and likelihood of recommendation.

**Table: the percentage of respondents who were extremely likely or likely to recommend a personal health budget/integrated personal budget, split by whether or not they were able to choose the budget option they wanted**

Question	Yes	No
Were you able to choose the option you wanted for managing your personal health budget/integrated personal budget?	85%	72%

Finally, relationship between perception of restrictions on how the money could be spent and the likelihood of recommendation is shown below.

**Table: the percentage of respondents who were extremely likely or likely to recommend a personal health budget/integrated personal budget, split by the type of restrictions on their budget**

Question	Yes, and reasonable	No restrictions	Yes, and seemed unreasonable
Are / were there any restrictions on how you are / were allowed to spend your personal health budget/integrated personal budget?	89%	89%	56%

Further detail on the above questions can be found in the [key features](#) section.

The association between strength of positive response to questions relating to key features and the likelihood of recommendation suggests that **quality** of experience matters. The results this time round mirror those of last year’s survey and serve therefore to strengthen any discussion around the link between these questions and respondents’ overall likelihood of recommendation.

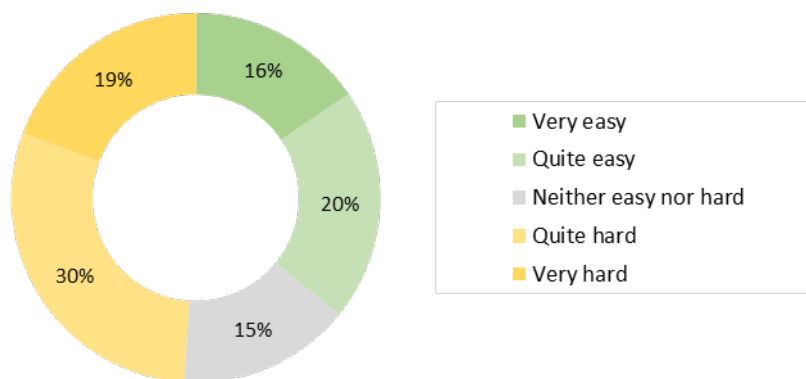
## Managing personal assistants

Questions 39 to 44 asked respondents about their experience of managing their own staff.

**72%** of respondents said that they employed / had employed their own personal assistants.

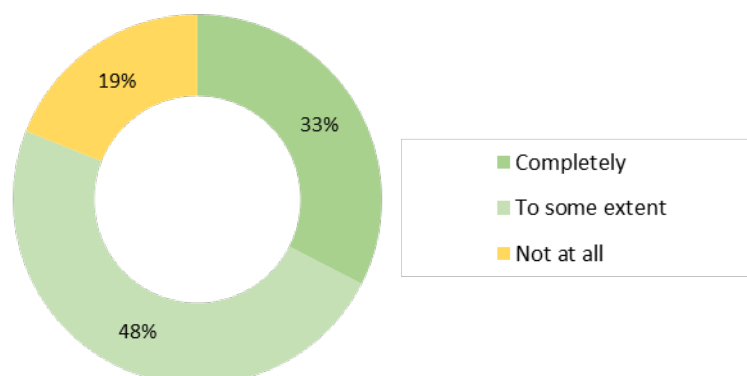
**36%** of respondents said that it was very or quite easy to recruit their own personal assistant/s; **49%** said it was very or quite hard.

### Q40. How easy was it to recruit your personal assistant/s?



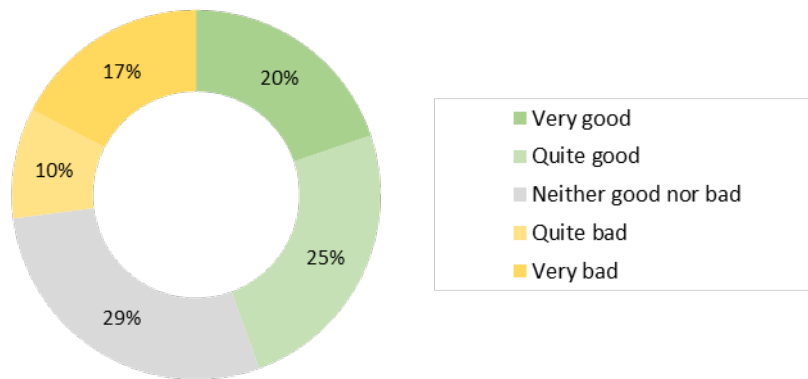
**81%** said that they felt able to set the most appropriate terms and conditions (including pay) for their personal assistant/s completely or to some extent.

### Q41. To what extent do you feel you were able to set the most appropriate terms and conditions (including pay) for your personal assistant/s?



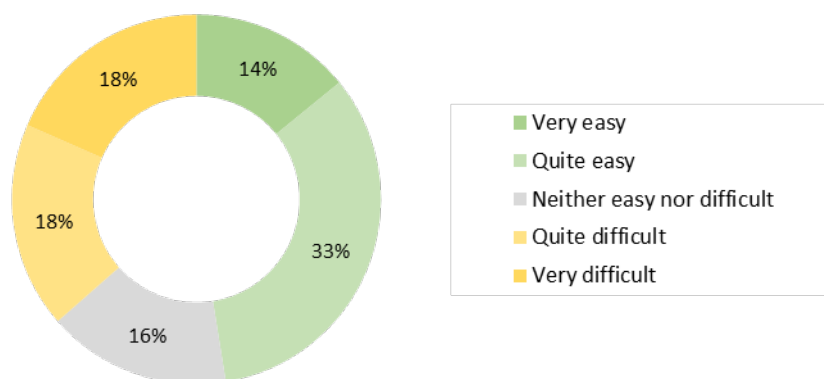
**44%** of respondents said that the training and support they received on managing their own staff was good.

**Q42. How good was the training and support you received on managing your own staff?**



**47%** of respondents said it was very or quite easy to access training for their own staff.

**Q43. How easy is it for you to access training for your own staff?**



A new question for 2019 asked about who provided training for delegated healthcare tasks, if applicable.

**Q44: If you have accessed training for delegated healthcare tasks for your own staff, who provided the training?**

Training provider	30%
Local health professional employed by CCG or local authority	18%
Family member	16%
Health professional employed as part of the personal health budget/integrated personal budget	10%
Voluntary sector organisation	5%
Other	20%

Free text for the 'Other' portion indicated that some respondents accessed this training from multiple sources, and the question structure would have been more useful to respondents if it had allowed multiple selection.

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'[Being an employer is...] tricky and difficult, more so at the beginning. Flexibility, trust, honesty and reliability are crucial to ensure support is provided in an ordinary personalised way that works whilst keeping the person safe and the PA confident.'

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'The hardest thing is recruitment [of PAs]. I really think my PA's deserve higher pay, they are brilliant and my life would be non-existent without them.'

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'Training pathways for PA's needs to be more transparent and readily available and communicated to budget holders.'

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'PHB has dramatically changed things. With the support to choose and train PA's to manage health care tasks and safe moving and handling, we have a close, reliable and consistent team...'

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## Some key areas for improvement

Though this report primarily covers the quantitative data from the personal health budget/integrated personal budget questionnaire, the extensive qualitative feedback was analysed to identify areas where people were telling us the process needed to be improved. NHS England and NHS Improvement will review this feedback in depth; below is a selection of the themes identified that relate to some of the quantitative questions.

### Not able to choose preferred budget option

**18%** of personal health budget/integrated personal budget survey respondents said that they were not able to choose the option they wanted to manage the budget. The overall experience scores for respondents by response to this question are shown in the following table.

**Table: the average results for Q58, Q59 and Q60, split by whether or not respondents were able to choose they budget option they wanted**

Question	No (18%)	Yes (82%)
Q58. How would you rate the overall experience of getting a personal health budget/integrated personal budget?	4.7	6.7
Q59. How would you rate your overall experience of the outcome and what you have achieved by having a personal health budget/integrated personal budget?	6.2	8.1
Q60. How likely would you be to recommend a personal health budget/integrated personal budget to someone else? Percentage answering “Extremely Likely” or “Likely”	72%	85%

In addition to respondents feeling they could not choose the preferred budget option, a second question asked which budget options people had received information on, and the responses to that showed that people were mainly given information on the direct payment options – only **24%** of respondents were informed about third party budget held by a provider organisation, and **19%** about notional budgets held by the council or NHS.

## Unreasonable restrictions

**27%** of personal health budget/integrated personal budget survey respondents said there were unreasonable restrictions on how they were allowed to spend their budget. The overall experience scores for respondents by response to this question are shown in the following table.

**Table: the average results for Q58, Q59 and Q60, split by the type of restrictions on the budget**

Question	Unreasonable restrictions	No (or reasonable) restrictions
Q58. How would you rate the overall experience of getting a personal health budget/integrated personal budget?	4.3	6.9
Q59. How would you rate your overall experience of the outcome and what you have achieved by having a personal health budget/integrated personal budget?	5.6	8.4
Q60. How likely would you be to recommend a personal health budget/integrated personal budget to someone else? Percentage answering "Extremely Likely" or "Likely"	56%	89%

In the free text, people also identified that they were unclear what they could spend the money on, and that this changed over time e.g. some things that had been allowed were no longer allowed. As noted earlier in this report, there is considerable variation amongst respondents on what they could and could not spend money on; some respondents were aware of this variation, and felt it was unfair.

## Difficulty finding information

**42%** of personal health budget/integrated personal budget survey respondents said that it was quite difficult or very difficult to find more information about personal health budgets/integrated personal budgets. The overall experience scores for respondents by response to this question are shown in the following table.

**Table: the average results for Q58, Q59 and Q60, split by difficulty of finding more information about personal health budgets/integrated personal budgets**

Question	Quite (or very) difficult	Neutral, quite (or very) easy
Q58. How would you rate the overall experience of getting a personal health budget/integrated personal budget?	4.3	7.3
Q59. How would you rate your overall experience of the outcome and what you have achieved by having a personal health budget/integrated personal budget?	6.6	8.2
Q60. How likely would you be to recommend a personal health budget/integrated personal budget to someone else? Percentage answering "Extremely Likely" or "Likely"	67%	87%

Difficulty in finding information was highlighted in the qualitative feedback. There were related themes, such as: people struggling to contact staff; people feeling staff did not understand the process; not enough support to organise care and support; and a lack of communication throughout. A number of respondents identified that more peer support would have been helpful.

## Other themes

In addition to those described in more detail above, the following themes were also identified:

- Process is too complex and takes too long
- Insufficient money in the budget, including no increases to reflect inflation over time
- Recruiting personal assistants, and being an employer is challenging, and there is a lack of support for this.

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'The application took too long - it took a year to receive the funds. In this time my health has declined even more.'

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## Respondent details

For each of the demographic questions, the comparison for Q58-60 is shown, which are the two overall experience rating questions and the likelihood of recommendation.

Note that in all cases, respondents were asked to complete these demographic questions for the person they were answering the survey on behalf of and not themselves (if they were completing the survey on somebody else's behalf). However, for ease of description, the term 'respondents' is used for these demographic questions.

### Gender

**184 (45%)** respondents were male and **229 (55%)** were female. This proportion of female respondents is higher than in the population as a whole when comparing to the 2011 UK census<sup>2</sup>.

**Table: the average results for Q58, Q59 and Q60, split by gender**

Question	Male	Female
Q58. How would you rate the overall experience of getting a personal health budget/integrated personal budget?	6.3	5.8
Q59. How would you rate your overall experience of the outcome and what you have achieved by having a personal health budget/integrated personal budget?	7.5	7.4
Q60. How likely would you be to recommend a personal health budget/integrated personal budget to someone else? Percentage answering "Extremely Likely" or "Likely"	80%	77%

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<sup>2</sup> Visit this link to see statistical bulletin:

<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/2011censuspopulationestimatesfortheunitedkingdom/2012-12-17>

## Ethnicity

Of the respondents, **368 (90%)** described their ethnic group as White English, Welsh, Scottish, Northern Irish or British. **10 (2%)** described their ethnic group as Indian, while **31 (8%)** described their ethnic group as being from a wide range of other ethnic groups.

As with last year's survey, the proportion of these groups is not directly comparable with the groups reported in the last UK census of 2011<sup>3</sup> and our sample appears to underrepresent Black, Asian and Minority Ethnic groups (which were 20% in the 2011 census).

**Table: the average results for Q58, Q59 and Q60, split by White/BME**

Question	White	BME
Q58. How would you rate the overall experience of getting a personal health budget/integrated personal budget?	6.1	5.8
Q59. How would you rate your overall experience of the outcome and what you have achieved by having a personal health budget/integrated personal budget?	7.5	7.3
Q60. How likely would you be to recommend a personal health budget/integrated personal budget to someone else? Percentage answering "Extremely Likely" or "Likely"	79%	77%

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<sup>3</sup> Visit this link to see statistical bulletin:

<https://www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity>

## Disability

Respondents could select more than one option and reported that they had the following long-standing conditions:

- **194 (46%)** said that they had a long-term neurological condition e.g. spinal injury, cerebral palsy
- **158 (38%)** said that they had a long-term physical disability, such as loss of a limb, blindness
- **146 (35%)** said that they had a progressive degenerative condition such as muscular dystrophy, motor neurone disease, dementia
- **118 (28%)** said that they had a learning disability
- **104 (25%)** said that they had a mental health problem
- **90 (21%)** said that they had a long-term health condition such as HIV, diabetes, COPD, chronic heart disease.

**Table: the average results for Q58, Q59 and Q60, split by type of condition**

Question	Mental health problem and/or learning disability ONLY	All those with any other combination of long-term condition(s)
Q58. How would you rate the overall experience of getting a personal health budget/integrated personal budget?	6.3	6.0
Q59. How would you rate your overall experience of the outcome and what you have achieved by having a personal health budget/integrated personal budget?	7.1	7.4
Q60. How likely would you be to recommend a personal health budget/integrated personal budget to someone else? Percentage answering “Extremely Likely” or “Likely”	85%	77%

## Sexual orientation

Asked about their sexuality, **57 (14%)** said they would prefer not to say. **332 (81%)** said that they were heterosexual/straight. **20 (5%)** said that they were gay/lesbian, bisexual or other. This profile is slightly different than the latest overall UK population (as identified by the Office of National Statistics<sup>4</sup>).

The numbers for those who said that they were not heterosexual are small, so the comparison should be treated with caution.

**Table: the average results for Q58, Q59 and Q60, split by sexuality**

Question	Heterosexual/ straight Respondents: 332	All other sexualities Respondents: 20
Q58. How would you rate the overall experience of getting a personal health budget/integrated personal budget?	6.2	4.5
Q59. How would you rate your overall experience of the outcome and what you have achieved by having a personal health budget/integrated personal budget?	7.6	6.0
Q60. How likely would you be to recommend a personal health budget/integrated personal budget to someone else? Percentage answering "Extremely Likely" or "Likely"	80%	71%

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<sup>4</sup> Visit this link to see statistical bulletin: <https://www.ons.gov.uk/peoplepopulationandcommunity/cultural-identity/sexuality>

## Geography

Respondents were from every region of the country. There weren't enough respondents overall to allow a meaningful comparison at clinical commissioning group level, but it is possible by region.

**Table: the average results for Q58, Q59 and Q60, split by region**

Region (Respondents)	Q58. How would you rate the overall experience of getting a personal health budget/integrated personal budget?	Q59. How would you rate your overall experience of the outcome and what you have achieved by having a personal health budget/integrated personal budget?	Q60. How likely would you be to recommend a personal health budget/integrated personal budget to someone else?  Percentage answering "Extremely Likely" or "Likely"
East Midlands (49)	5.7	7.0	73%
East of England (30)	5.8	8.1	79%
Greater London (41)	5.6	6.9	74%
North East (52)	7.0	8.0	88%
North West (75)	5.7	7.1	74%
South East (43)	5.8	7.0	69%
South West (54)	6.0	8.1	90%
West Midlands (50)	7.2	8.1	80%

## Age

For the respondents who provided the year of birth of the budget holder the age bandings are as follows:

- **15 (4%)** aged under 16
- **63 (15%)** between the age of 16-24
- **65 (16%)** between the age of 25-34
- **42 (10%)** between the age of 35-44
- **46 (11%)** between the age of 45-54
- **60 (14%)** between the age of 55-64
- **68 (16%)** between the age of 65-74
- **29 (7%)** between the age of 75-84
- **18 (4%)** aged 85+
- **13 (3%)** did not provide a year of birth or it was not available

These bands have been grouped into broader age bands due to the low number of respondents in each group. The bandings being used are:

- 16-34
- 35-64
- 65+

**Table: the average results for Q58, Q59 and Q60, split by age band**

Question	16-34	35-64	65+
Q58. How would you rate the overall experience of getting a personal health budget/integrated personal budget?	5.9	5.9	6.4
Q59. How would you rate your overall experience of the outcome and what you have achieved by having a personal health budget/integrated personal budget?	7.1	7.4	8.1
Q60. How likely would you be to recommend a personal health budget/integrated personal budget to someone else? Percentage answering "Extremely Likely" or "Likely"	76%	76%	85%

## Hearing from people about their suggestions for improvement

A selection of suggestions from respondents follows. NHS England and NHS Improvement will review the qualitative feedback in detail to identify local and national quality improvement activity.

### Peer support

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‘Facilitating a support network among comparable PHB holders for circulation of information and help.’

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‘An online forum of PHB holders in the local area who could ask each other questions and share experiences so that you can learn from one another, rather than address all queries to the CCG...’

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‘Peer groups. A basic information DVD made available to all new potential personal health budget clients, including helpful resources providing qualitative “how to” guidance. Audio examples from present personal health budget users down-loadable from local CCG support teams...’

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### Clearer information

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‘More information, better guidance on what they can be used for, more consistency on what they can be used for, less interrogation as to why I should have funding, more caring attitude rather than making me feel like I shouldn't have help.’

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‘By providing accurate plain English information as a matter of course and speed up the bureaucratic system when people need support.’

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‘Clear written information should be provided by CCGs. Service users need to know what a PHB is, how to get one and how it can be provided, e.g. by direct payments. They need to be told personal stories of how they can be used and provided with examples of care and support plans.’

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## Staff training and communication

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'Better communication, trained staff and increased numbers of personnel.'

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'Training for the panels and staff approving and providing them about outside the box thinking and true personalisation.'

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'Having a named clinician, be given the correct information at the start of the process and agreement that is made by myself and the CCG with terms and conditions attached to them.'

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'More communication and things to be done quicker.'

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'By incorporating awareness and understanding of the need to balance a reviewable care plan with a sometimes untidy, unreviewable life.'

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## Next steps

NHS England and NHS Improvement will use the findings of this survey to inform future work with local clinical commissioning groups. The continuing work will support greater access and further improve people's experiences of obtaining and having personal health budgets and integrated personal budgets. This includes ensuring compliance with the new legal rights to personal health budgets for those requiring bespoke wheelchairs and those receiving support for their mental health under section 117 of the Mental Health Act. This is all within the ambition to extend the number of people benefitting from a personal health budget or integrated personal budget to 200,000 by 2023/24.

Quality Health is a specialist health and social care survey organisation, working for the public, private and not-for-profit sectors, in the UK and overseas.

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