Personal Health Budget and Integrated Personal Budget Survey 2018

Results Summary
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**Introduction**

We are hugely grateful to the personal health budget/integrated personal budget users, and their carers, who responded to this survey.

The survey is part of a wider NHS England strategy to understand progress and to hear people’s perceptions of the quality of their local personal health budget and integrated personal budget offer. NHS England intends to use the findings from the survey to help shape national and local improvement activity.

The independent survey was commissioned by NHS England. The questionnaire was designed by Quality Health, working closely with a co-production working group involving current personal health budget/integrated personal budget holders, and tested with a group of volunteers. Quality Health implemented and analysed the survey.
Executive summary

This report starts by reviewing the methodology of the survey, and then sets the context for the report by explaining the key features of personalised care. The key features were co-produced with people with lived experience of personalised care. They describe what a person should expect to experience from the process of getting and then having a personal health budget. They have been used to contextualise the findings from the survey.

Detailed responses to the questionnaire then follow. The report concludes with respondent details and some direct illustrative quotes.

Personal health budget/integrated personal budget holders rated their experience of the outcome and what they have achieved by having a personal health budget/integrated personal budget at an average of 7.3 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 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:

- **77%** said they were likely or extremely likely to recommend a personal health budget/integrated personal budget to someone else
- **89%** said that their personalised care and support plan reflected what mattered to them to some extent or completely
- **86%** said that they had achieved what they wanted as a result of their plan, to some extent or completely.

Some of the findings have provided key areas for improvement:

- **60%** said that the overall time taken between starting the process of getting a personal health budget/integrated personal budget and having the budget up and running was too slow
- **41%** said that it was quite difficult or very difficult to find more information about personal health budgets/integrated personal budgets once they decided they wanted this
- **47%** of respondents who employed personal assistants, said that it was quite hard or very hard to recruit their personal assistant(s).

“I feel lucky to have it. It’s changed my life.”
Methodology and structure

The survey was run on-line, 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 publicised through networks of patient organisations and other groups, newsletters, and social media.

The fieldwork for the survey was undertaken between February and April 2018.

A Freephone helpline was available for respondents to ask questions about the survey, to enable them to complete their questionnaires over the phone, and to provide access to a translation and interpreting facility for those whose first language was not English (although no respondents took up this option).

The questionnaire had 61 questions covering:

1. Finding out about budgets
2. Getting clear information*
3. Understanding your needs
4. Working out money*
5. Creating a care plan*
6. Organising your care*
7. Managing your own staff*
8. Monitoring and review*
9. Your overall experience*
10. Demographic information
11. Contact preferences.

* Questions were primarily multiple choice – single selection and multiple selection – but the survey also invited respondents to provide written answers for eight of the questions; those sections with an asterisk in the list above had a related qualitative question. Though the extensive qualitative feedback is not covered in this report, it will be used by NHS England alongside the quantitative data to inform improvement activity.

Please note that the percentages in this report have been rounded to the nearest percentage.
Response numbers

There were 390 responses to the survey in total. 164 (42%) of these were filled in directly by the person that the questionnaire related to. The rest were filled in on their behalf by somebody else, usually either a relative/friend (32%), a parent carer (32%), or a family carer (26%).

337 (87%) respondents had a personal health budget/integrated personal budget; and another 17 (4%) had had one in the past.

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

- 205 (53%) respondents said that they had used a direct payment held by them, a family member or friend
- 89 (23%) respondents said that they had used a direct payment held by someone else on their behalf (sometimes known as a managed account)
- 57 (15%) respondents said that they had used a third party budget held by a provider organisation (sometimes known as an individual service fund)
- 44 (11%) respondents said that they had used a pre-paid card
- 37 (9%) respondents said that they had used a notional budget held by the council or NHS
- 13 (3%) respondents said that they had used another option to manage it.

80% of respondents said that they were able to choose the option they wanted for managing their personal health budget/integrated personal budget. However, not everyone had been given information on all the options.
Report context: the key features of a personalised and integrated approach to care

The key features were 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 and in italics 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, therefore they have been used to contextualise the findings from this survey.

1For people to have a personalised and integrated approach to care a person should:

- 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 the 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.

1Visit this link to see the full PDF: https://digital.nhs.uk/binaries/content/assets/legacy/pdf/k/6/guidance-for-phb-data-collection-2018.19-final.pdf
**Survey results**

This section looks at the survey questions relating to most of the 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’ experience of the information, advice and support provided.

**Q5. How did you first hear about personal health budgets/integrated personal budgets?**

<table>
<thead>
<tr>
<th>Source</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>From social services</td>
<td>28%</td>
</tr>
<tr>
<td>From my healthcare professional</td>
<td>26%</td>
</tr>
<tr>
<td>I found out for myself – online</td>
<td>12%</td>
</tr>
<tr>
<td>From a voluntary organisation/charity</td>
<td>10%</td>
</tr>
<tr>
<td>From family/friends</td>
<td>5%</td>
</tr>
<tr>
<td>From another personal health budget/integrated personal budget holder</td>
<td>3%</td>
</tr>
<tr>
<td>I found out for myself – printed information/leaflet</td>
<td>1%</td>
</tr>
<tr>
<td>From my GP</td>
<td>1%</td>
</tr>
<tr>
<td>Other</td>
<td>10%</td>
</tr>
<tr>
<td>Don’t know/can’t remember</td>
<td>4%</td>
</tr>
</tbody>
</table>

42% of respondents said that, once they decided they wanted more information about personal health budgets/integrated personal budgets in their area, this was easy to find.

**Q6. Once you decided you wanted more information about personal health budgets/integrated personal budgets in your area, how easy was this to find?**

- Very easy: 28%
- Quite easy: 19%
- Neither easy nor difficult: 22%
- Quite difficult: 17%
- Very difficult: 15%

“I found face-to-face meeting invaluable. I was able to ask questions in a relaxed atmosphere within my home and having a named adviser I found extremely useful so I could continue to ask questions/gather information as I moved forwards with the PHB.”
52% of respondents said that it was easy to make contact with someone who could tell them more about personal health budgets/integrated personal budgets.

Q7. How easy was it to make contact with someone who could tell you more about personal health budgets/integrated personal budgets?

64% of respondents said that they were given enough information about personal health budgets/integrated personal budgets.

28% of respondents said that they always received useful information, at the time they needed it, to help them manage their health and wellbeing.

Q10. To what extent do you receive useful information, at the time you need it, to help you manage your health and wellbeing?

There was a follow-up question that asked how this information was provided. This was a multiple selection question. The most frequently selected options – in order – were ‘Verbally, face-to-face’, ‘Over the phone’, ‘Via email’ and ‘On paper’.
98% of respondents said that the information they received about personal health budgets/integrated personal budgets was clear.

Q12. How clear was the information you were given about personal health budgets/integrated personal budgets?

These results suggest that while it may be challenging for people to find the information they need, once they do receive this information it is of excellent quality. Only the 104 respondents who answered ‘Completely’ for Q10 were routed to this question.

Most respondents (66%) had been given information on direct payments held by themselves, a family member or friend. Fewer respondents had been given information on third party budgets held by a provider organisation (25%) or notional budgets held by the council or NHS (19%).

Q27. Which of the following options for managing a personal health budget/integrated personal budget were you given information on? (multiple selection question)

<table>
<thead>
<tr>
<th>Option</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct payment held by me, a family member or friend</td>
<td>66%</td>
</tr>
<tr>
<td>Direct payment held by someone else on my behalf</td>
<td>39%</td>
</tr>
<tr>
<td>Third party budget held by a provider organisation</td>
<td>25%</td>
</tr>
<tr>
<td>Notional budget held by the council or NHS</td>
<td>19%</td>
</tr>
<tr>
<td>Pre-paid card</td>
<td>15%</td>
</tr>
<tr>
<td>Other</td>
<td>2%</td>
</tr>
<tr>
<td>Don’t know</td>
<td>3%</td>
</tr>
<tr>
<td>Not applicable</td>
<td>6%</td>
</tr>
</tbody>
</table>

“There was conflicting information; everyone knew it was supposed to be a good thing, but no one person had all the information. It would have been really useful to have an information portal online where I could ask questions when they occurred to me rather than trying to remember them for the next meeting. I would also be able to change the format/colour/contrast of the information to make it more accessible for me.”
58% of respondents said the support they received on managing their personal health budget/integrated personal budget was good.

Q32. In your opinion, how good was the support you received on managing your personal health budget/integrated personal budget?

[Diagram showing percentages: Very good: 34%, Quite good: 25%, Neither good nor bad: 21%, Quite bad: 19%, Very bad: 17%]

40% 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 good.

Q33. 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?

[Diagram showing percentages: Very good: 22%, Quite good: 21%, Neither good nor bad: 19%, Quite bad: 17%, Very bad: 9%]
Key feature: Be valued as an active participant in conversations and decisions about their health and wellbeing.

82% of respondents said that they thought their health needs were understood.

75% of respondents said that they thought their well-being needs were understood.

89% of respondents said that they felt they had been involved in the assessment of their health and well-being needs.

87% of respondents said that they felt their health and well-being needs had been reflected in their personal health budget/integrated personal budget.
Key feature: Be central in developing their personalised care and support plan and agree who is involved.

81% of respondents said that they were involved as much as they wanted to be in creating their personalised care and support plan.

Q23. Were you involved as much as you wanted to be in creating your personalised care and support plan?

- Yes, definitely: 52%
- Yes, to some extent: 29%
- No, I would like to have been more involved: 19%

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

“The way I was involved in this process was excellent there should be more stuff like this.”
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.

89% of respondents said that their plan reflected what mattered to them.

Q24. 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.

61% 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.

Q18. Did you understand at the start of the process how much money would be available in your personal health budget/integrated personal budget?

62% of respondents said that they understood the process for deciding the amount of money available.

“It’s difficult to have a good support plan when the plan is based around what works best for the organisation. I don’t really believe that my area knows the true value of a personalised care and support plan. I think if they did they would do it much better…”
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.

79% of respondents said that the money available in their budget was sufficient for their identified needs.

Q21. In your opinion, is/was this sufficient money for your identified needs?

- Yes, absolutely: 38%
- Yes, to some extent: 21%
- No, not at all: 41%

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.

Q28. Which of the following options have you used to manage a personal health budget/integrated personal budget? (multiple selection question)

- Direct payment held by me, a family member or friend: 53%
- Direct payment held by someone else on my behalf: 23%
- Third party budget held by a provider organisation: 15%
- Pre-paid card: 11%
- Notional budget held by the council or NHS: 9%
- Other: 3%
- Don’t know: 2%
- Not applicable: 3%

“Indicative budget should be known from the outset. Should be told to use money in a personalised way and less of the restrictive ideology.”

“The PHB manager provided clear information on the indicative budget during the process of applying for the PHB, what it could be used for and how the process and timescales worked. Support/guidance was provided to compile the budget.”
10% of respondents who answered this question selected ‘I was not given any of the options above’.

80% of respondents 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 (Q27 earlier in this report).

**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.

76% of respondents said that there were no restrictions on how they were allowed to spend their 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.

**Q30. Are/were there any restrictions on how you are/were allowed to spend your personal health budget/integrated personal budget?**

<table>
<thead>
<tr>
<th>Response</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, but they seem/seemed reasonable to me</td>
<td>48%</td>
</tr>
<tr>
<td>Yes, and they seem/seemed unreasonable to me</td>
<td>24%</td>
</tr>
<tr>
<td>No</td>
<td>29%</td>
</tr>
</tbody>
</table>

78% of respondents said that they had enough flexibility to spend different amounts of money in different months.

**Q31. Do/did you have enough flexibility to spend different amounts of money in different months?**

- Yes, completely: 39%
- Yes, to some extent: 39%
- No, not at all: 22%
87% of respondents said that they understood what the money could be spent on, absolutely or to some extent.

86% of respondents said they had achieved what they wanted to as a result of their plan.

Q51. Have you achieved what you wanted to as a result of your plan?
Recommendation and quality

Questions 44 to 55 asked respondents about their overall experience of getting and having a personal health budget/integrated personal budget.

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

Q54. 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.)

Q55. 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.)
Finding: Respondents who rated getting/having a personal health budget/integrated personal budget more highly were more likely to recommend one to someone else.

Q55. Would you recommend a personal health budget/integrated personal budget to someone else?

<table>
<thead>
<tr>
<th>Extremely likely</th>
<th>Likely</th>
<th>Neither likely or unlikely</th>
<th>Unlikely</th>
<th>Extremely unlikely</th>
</tr>
</thead>
<tbody>
<tr>
<td>6%</td>
<td>12%</td>
<td>25%</td>
<td>51%</td>
<td>4%</td>
</tr>
</tbody>
</table>

Looking at the relationship between Q53 and Q54, and whether the budget holder would go on to recommend a personal health budget/integrated personal budget in Q55:

- Of the 200 respondents who rated getting a personal health budget/integrated personal budget as 7 or higher, 140 were extremely likely to recommend one and 45 likely to recommend one (93% across both) – only 2 said they would not
- Of the 274 respondents who rated the outcome and achievements of having a personal health budget/integrated personal budget as 7 or higher, 176 were extremely likely to recommend one and 74 were likely to recommend one (91% across both) – only 2 said they would not.

This suggests there may be an association between two questions in each pair, indicating that using the question ‘Would you recommend a personal health budget/integrated personal budget to someone else?’ as a measure of quality is reasonable.

“The principals of flexibility, control and individualised care should be enshrined and the creeping culture of fear and risk should be challenged.”

“Thoughtful and considerate support has been much appreciated during a very difficult time. The support given and availability of someone at the end of the phone if needed has been important, especially when the legalities of ‘doing it right’ and staying within the approved care plan are new and difficult to manage...”
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 further looked at how strength of positive experience of certain key aspects of the process relates to how respondents answered the question ‘Would you recommend a personal health budget/integrated personal budget to someone else?’. This is shown in the table below.

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 somebody else.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes, absolutely or Yes, completely</th>
<th>Yes, to some extent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you understand at the start of the process how much money would be available in your personal health budget/integrated personal budget?</td>
<td>91%</td>
<td>82%</td>
</tr>
<tr>
<td>In your opinion, is/was this sufficient money for your identified needs?</td>
<td>93%</td>
<td>74%</td>
</tr>
<tr>
<td>Were you involved as much as you wanted to be in creating your personalised care and support plan?</td>
<td>91%</td>
<td>67%</td>
</tr>
<tr>
<td>In your opinion, how well does/did your plan reflect what matters to you?</td>
<td>91%</td>
<td>68%</td>
</tr>
<tr>
<td>Do/did you have enough flexibility to spend different amounts of money in different months?</td>
<td>90%</td>
<td>78%</td>
</tr>
<tr>
<td>Have you achieved what you wanted to as a result of your plan?</td>
<td>94%</td>
<td>73%</td>
</tr>
</tbody>
</table>

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>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Were you able to choose the option you wanted for managing your personal health budget/integrated personal budget?</td>
<td>84%</td>
<td>51%</td>
</tr>
</tbody>
</table>
Finally, relationship between perception of restrictions on how the money could be spent and likelihood of recommendation is shown below.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes, but reasonable</th>
<th>No restrictions</th>
<th>Yes, and seemed unreasonable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are/were there any restrictions on how you are/were allowed to spend your personal health budget/integrated personal budget?</td>
<td>90%</td>
<td>82%</td>
<td>48%</td>
</tr>
</tbody>
</table>

Further detail on the questions above can be found in the key features section.

The association between strength of positive response to questions relating to the key features and likelihood of recommendation suggests that quality of the experience matters.
Some key areas for improvement

Finding: Respondents felt the process of getting a budget up and running was too slow.

Q44. How long did it take between starting the process of getting a personal health budget/integrated personal budget, and having your budget actually up and running?

<table>
<thead>
<tr>
<th>Time Interval</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than a month</td>
<td>7%</td>
</tr>
<tr>
<td>1 to 3 months</td>
<td>23%</td>
</tr>
<tr>
<td>3 to 6 months</td>
<td>23%</td>
</tr>
<tr>
<td>6 to 12 months</td>
<td>15%</td>
</tr>
<tr>
<td>More than 12 months</td>
<td>20%</td>
</tr>
<tr>
<td>Don’t know/can’t remember</td>
<td>9%</td>
</tr>
<tr>
<td>Not applicable</td>
<td>4%</td>
</tr>
</tbody>
</table>

60% of respondents found the time taken was too slow.

Finding: The majority of respondents had access to a single named person, but respondents did not always find the person easy to contact, and also experienced changes to this person.

69% of respondents said that they had access to a single named person at their Clinical Commissioning Group to give them information and support about their personal health budget/integrated personal budget.

48% of respondents said that it was easy to contact this person.

43% of respondents said that there was a change to the named person since they first received their personal health budget/integrated personal budget.

“It would be great to have a named person to build a relationship with. Someone who knows me, knows the challenges and is familiar with how I want to live rather than a string of strangers...”
Managing personal assistants

Questions 35 to 40 asked respondents about their experience of employing personal assistants (PAs). **76%** of respondents said they do/did employ their own PAs.

**42%** of respondents found it easy to recruit their personal assistant/s.

Q36. How easy was it to recruit your personal assistant/s?

83% of respondents felt able to set the most appropriate terms and conditions (including pay) for their personal assistant/s.

Q37. To what extent do you feel you were able to set the most appropriate terms and conditions (including pay) for your personal assistant/s?

“**It can be hard to find compatible help but when you do find someone who is tactful, sympathetic and most importantly can learn to anticipate your needs it is liberating beyond belief. On the other hand if you don’t gel with that person it can be quite difficult and stressful.”**
45% of respondents said the training and support they received on managing their own staff was good.

Q38. How good was the training and support you received on managing your own staff?

46% of respondents said it was easy for them to access training for their own staff.

Q39. How easy is it for you to access training for your own staff?

“Training was quite difficult to access in the beginning - especially training in clinical tasks. This is now available and is vitally important to ensure my PAs are competent in their duties as well as feeling they are valued and supported within their work.”
Respondent details

Gender

167 (44%) respondents were male and 209 (56%) female. This proportion of female respondents is higher than in the population as a whole.

There are few differences in question scores by gender. For example, when asked whether they would recommend a personal health budget/integrated personal budget to someone else, 75% of male respondents, and 70% of female respondents, answered positively.

The three questions with the biggest differences (positive responses*) by gender are as follows:

<table>
<thead>
<tr>
<th>Question</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q36. How easy was it to recruit your personal assistant/s?</td>
<td>48%</td>
<td>37%</td>
</tr>
<tr>
<td>Q46. Do/did you have access to a single named person at your Clinical Commissioning Group (CCG) to give you information and support about your personal health budget/integrated personal budget?</td>
<td>75%</td>
<td>64%</td>
</tr>
<tr>
<td>Q30. Are/were there any restrictions on how you are/were allowed to spend your personal health budget/integrated personal budget?</td>
<td>83%</td>
<td>73%</td>
</tr>
</tbody>
</table>

*Refers to a combined score of the best two response options e.g. Very easy and Quite easy.
Ethnicity

Of the respondents, **321 (86%)** described their ethnic group as White English, Welsh, Scottish, Northern Irish or British. **13 (3%)** respondents described themselves as Indian. The remainder (**11%)** were from a wide range of other ethnic groups. The groups are not directly comparable with groups reported in the last UK census in 2011, but our sample appears to underrepresent Black, Asian and Minority Ethnic groups (19% in 2011, but almost certainly higher now).

The three questions with the biggest differences (positive responses*) by ethnicity are as follows:

<table>
<thead>
<tr>
<th>Question</th>
<th>White</th>
<th>BME</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Q39. How easy is it for you to access training for your own staff?</strong></td>
<td>47%</td>
<td>33%</td>
</tr>
<tr>
<td><strong>Q38. How good was the training and support you received on managing your own staff?</strong></td>
<td>46%</td>
<td>33%</td>
</tr>
<tr>
<td><strong>Q45. In your view, was the time taken...? [How long it took between the start of the process and having budget running.]</strong></td>
<td>41%</td>
<td>29%</td>
</tr>
</tbody>
</table>

*Refers to a combined score of the best two response options e.g. Very easy and Quite easy.
Disability

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

- **172 (44%)** said that they had a long-term neurological condition, e.g. a spinal injury, or cerebral palsy
- **141 (36%)** said that they had a long-term physical condition, such as the loss of a limb, or blindness
- **116 (30%)** said that they had a progressive or degenerative condition, such as muscular dystrophy, motor neurone disease, or dementia
- **97 (25%)** said that they had a long-term health condition, such as HIV, diabetes, COPD, or chronic heart disease
- **89 (23%)** said that they had a learning disability
- **77 (20%)** said that they had a mental health problem.

There are some differences in scores by disability, with those respondents with a mental health problem giving lower scores on many questions than those without a mental health problem.
**Sexuality**

Asked about their sexuality, **50 (13%)** respondents said that they would prefer not to say. **309 (82%)** were heterosexual/straight. **18 (5%)** were gay/lesbian, bisexual or other. This profile is slightly different than the latest overall UK position (as identified by the Office of National Statistics\(^1\)).

There are some differences in scores by sexuality. The three questions with the biggest differences (positive responses\(^*\)) by sexuality are as follows:

<table>
<thead>
<tr>
<th>Question</th>
<th>Heterosexual/Straight</th>
<th>All other sexualities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q29. Were you able to choose the option you wanted for managing your personal health budget/integrated personal budget?</td>
<td>85%</td>
<td>42%</td>
</tr>
<tr>
<td>Q15. In your opinion, do you think your well-being needs are/were understood?</td>
<td>81%</td>
<td>44%</td>
</tr>
<tr>
<td>Q19. Did you understand the process for deciding the amount of money available?</td>
<td>66%</td>
<td>39%</td>
</tr>
</tbody>
</table>

\(^1\) Visit this link to see statistical bulletin: https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/sexuality

*Refers to a combined score of the best two response options e.g. Yes, absolutely and Yes, to some extent.
Geography

Respondents were from every region of the country. There aren’t enough respondents overall to allow a meaningful comparison at Clinical Commissioning Group level, but this is possible by region – and there are some clear differences, the biggest being between the South East region and the West Midlands region. The three questions with the biggest differences (positive responses*) by region are as follows:

<table>
<thead>
<tr>
<th>Question</th>
<th>South East</th>
<th>West Midlands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q47. If so, how easy is/was it to contact this person? [Do/did you have access to a single named person at your Clinical Commissioning Group (CCG) to give you information and support about your personal health budget/integrated personal budget?]</td>
<td>42%</td>
<td>68%</td>
</tr>
<tr>
<td>Q18. Did you understand at the start of the process how much money would be available in your personal health budget/integrated personal budget?</td>
<td>52%</td>
<td>78%</td>
</tr>
<tr>
<td>Q19. Did you understand the process for deciding the amount of money available?</td>
<td>52%</td>
<td>70%</td>
</tr>
</tbody>
</table>

*Refers to a combined score of the best two response options e.g. Very easy and Quite easy.
Age

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

- **36 (9%)** said that they were between the age of 16-24
- **53 (14%)** said that they were between the age of 25-34
- **42 (11%)** said that they were between the age of 35-44
- **64 (17%)** said that they were between the age of 45-54
- **61 (16%)** said that they were between the age of 55-64
- **68 (18%)** said that they were between the age of 65-74
- **24 (6%)** said that they were between the age of 75-84
- **13 (3%)** said that they were 85+
- **20 (5%)** did not provide a year of birth or it was not available.

These have been further 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+

There is little difference between the three age groups overall, however, there are some significant differences for responses to certain questions. The biggest differences were between the 16-34 and the 35-64 age groups. The three questions with the biggest differences (positive responses*) are as follows:

<table>
<thead>
<tr>
<th>Question</th>
<th>16-34</th>
<th>35-64</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q45. In your view, was the time taken...? [How long it took between the start of the process and having budget running.]</td>
<td>45%</td>
<td>35%</td>
</tr>
<tr>
<td>Q15. In your opinion, do you think your well-being needs are/were understood?</td>
<td>81%</td>
<td>72%</td>
</tr>
<tr>
<td>Q36. How easy was it to recruit your personal assistant/s?</td>
<td>33%</td>
<td>40%</td>
</tr>
</tbody>
</table>

*Refers to a combined score of the best two response options e.g. Very easy and Quite easy.
“My [our] PHB works well but not because of the advice I was given but because of my former occupation and education. It is extremely stressful to be responsible for both another’s care and the employment of yet others. It is the best option for us but was a very steep learning curve at a point where I was so tired the alternative was residential care.”

“It gives me flexibility to manage changing needs.”

“Professionals should be more knowledgeable and better trained. Each applicant for a PHB should be assigned a knowledgeable and experienced facilitator to support them through the process. There should be a ‘pathway’ with timescales so everyone knows”

“Once I persuaded social services to get me a continuing care health assessment they quickly identified my health needs and listened. My PHB worker presented my case and I’ve had an amount of money that’s met my needs very flexibly and enabled my spouse to have a break. So far it has been very straightforward and the money matches my needs without being too much or too little so far. I think a lot has been down to knowledgeable staff throughout the process and being flexible with how I use it…”

“More respect and understanding of care and support plans [is needed]. Where the CCG see there everyone’s input as valid. Honesty. I think we avoid each other nowadays so we don’t create more work for each other, they fear we might ask questions they don’t know the answer to and we don’t want them medallng with something that works. They [should] see us as experts and not lay people as we so often get called, [there should be] consistency and transparency for all. We were lucky that our CCG believe in us and we would never move area as we wouldn’t take the risk of losing everything and going back to a bad place. Valuing people’s contributions.”

“Best thing I could have done.”
Quality Health is a specialist health and social care survey organisation, working for public, private and non-for-profit sectors, in the UK and overseas.

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