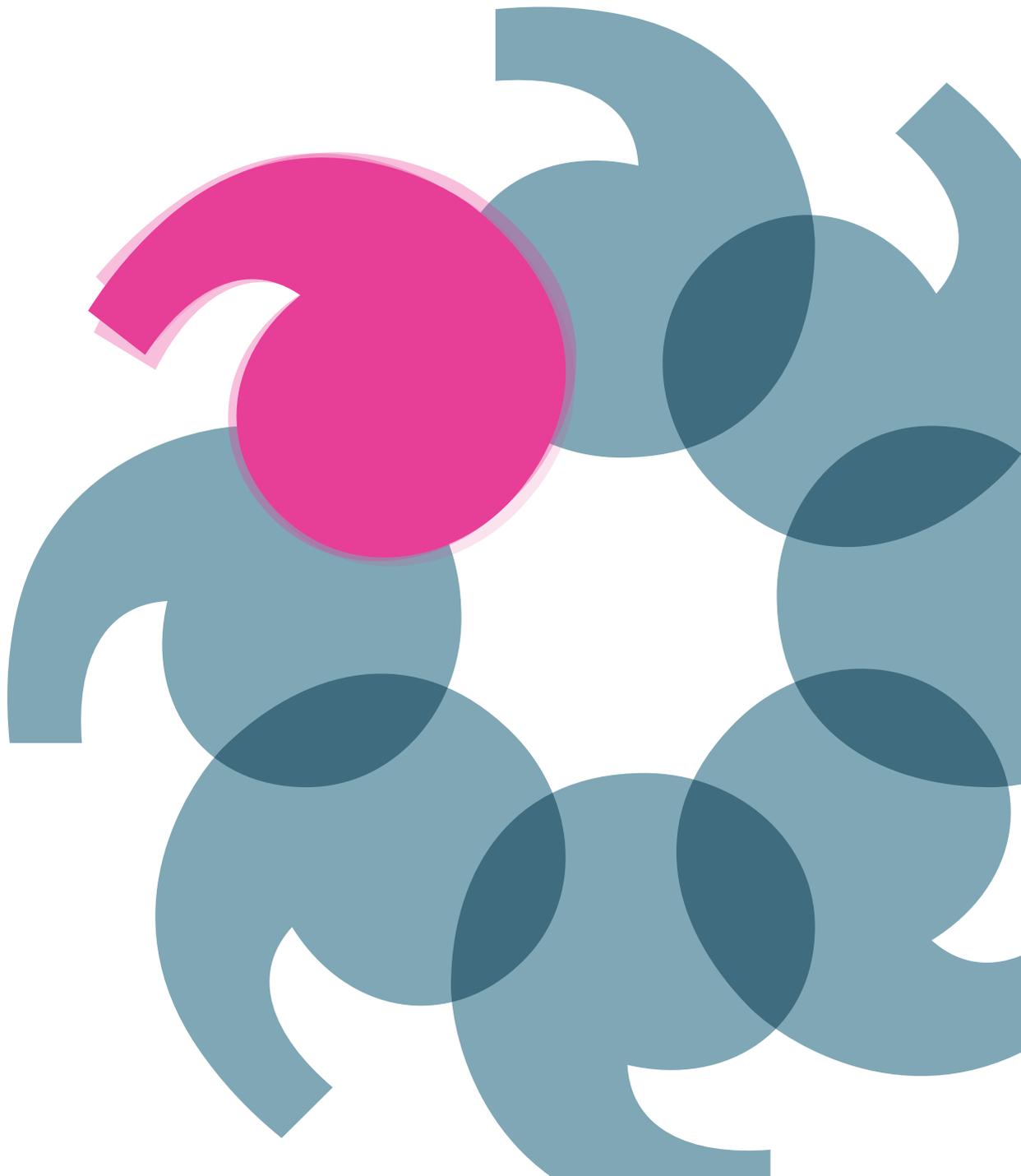


Personal Health Budgets

Gathering views from speakers of English as a second language



Diverse Communities Health Voice

Diverse Communities Health Voice is a consortium of local grass-roots black and minority ethnic community groups. The partnership is coordinated by Healthwatch Islington.

The partners participating in this project:

- ▶ Arachne Greek Cypriot Women's Group
- ▶ Community Language Support Services
- ▶ Eritrean Community UK
- ▶ Islington Bangladesh Association
- ▶ Islington Somali Community
- ▶ Jannaty
- ▶ Kurdish and Middle Eastern Women's Organisation
- ▶ Healthwatch Islington

www.healthwatchislington.co.uk

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Introduction

Islington Clinical Commissioning Group (CCG) invited Diverse Communities Health Voice to carry out this piece of research. The CCG wanted to better understand the support that is needed for local residents to enable them to take up a Personal Health Budget, should they want one. They were particularly keen to hear from people with additional barriers to accessing services. The Diverse Communities Health Voice partnership supports many local residents who don't have English as a first language. We spoke to residents with two or more long term health conditions.

What is a Personal Health Budget?

A Personal Health Budget is an amount of money to support your health and wellbeing needs, which is planned and agreed between you (or someone who represents you), and your local NHS team. A Personal Health Budget allows you to manage your healthcare and support, such as treatments, equipment and personal care, in a way that suits you. It may mean spending money differently so that you can get the care that you need.

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

- 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.

Who we spoke to

Partners were asked to speak to Islington residents who were registered with an Islington GP and had two or more conditions from the list below. Partners were asked to speak to adults who did not have English as a first language.

We spoke to a total of 63 local residents, none of whom were currently using a Personal Health Budget. 54 were responding for themselves and nine on behalf of someone for whom they cared.

Equalities data

Sex of respondents

Female	Male	No answer	Total
40	23	0	63

Age of respondents

17 & under	18-24	25-49	50-64	65-79	80+	No answer	Total
1	0	14	29	15	4	0	63

Disability status of respondents

Disabled	Not disabled	No answer	Total
46	159	2	207

Ethnicity of respondents

African	2
Arab	11
Bangladeshi	9
Eritrean	11
Greek	1
Greek - Cypriot	8

Iraqi Kurdish	2
Jamaican	1
Pakistani	1
Somali	16
Yemeni	1
Total	63

Language

Arabic	13
Bengali	9
English	1
Greek/ Greek Cypriot	9
Kurdish	1

Saho	1
Somali	18
Tigrinya	10
Urdu	1
Total	63

Conditions

In the list of conditions, depression and anxiety were listed together. Three respondents considered their depression and anxiety to be two separate conditions. 31 respondents had more than two conditions. One respondent had seven conditions.

Asthma	16
Atrial Fibrillation	2
Autism	1
Back pain	2
Blood pressure/ cholesterol	1
Cancer	6
Chronic heart disease	15
Chronic kidney disease	4
Chronic obstructive pulmonary disease	3
Dementia	3
Depression/ anxiety	39
Diabetes	39
Epilepsy	1

Heart failure	9
Incontinence	1
Migraines, headaches and dizziness	2
Osteoporosis	21
Painful joints	1
Parkinson's Disease	1
Physical disability	1
Pseudophakia	1
Rheumatism	1
Stroke	5
Tuberculosis	1
Total	176

Relationship with healthcare professionals

A Personal Health Budget is planned and agreed between the patient (or their representative) and the NHS team responsible for their care. For this process to be viable, effective communication is needed. Before we asked participants about Personal Health Budgets, we asked them a series of questions about their relationship with the professionals responsible for their care.

▶ Who in the health service are you talking to about your long term condition?

All respondents said they spoke to their GP. Most were speaking to a range of healthcare professionals. 43 of the 63 people we spoke to were also talking to at least one specialist or consultant about at least one of their conditions. Nine also reported talking to nurses.

▶ Do you feel that people in the health service know about you and your condition?

Most respondents (56) felt that the professionals did know about them and their condition. Often this was because they felt they were being seen on a regular basis, or because they had known the healthcare professional for a long time. Some felt that professionals knew them because their treatment was working. Several qualified their answer by saying that although professionals generally knew about them, some were less responsive to their queries, or less interested in them as patients. Those that said they weren't sure that professionals knew about them put this down to frequent changes of staff, or some staff knowing and some not. One respondent noted a lack of information about what to expect (such as how long to wait till you hear from the podiatry service), and another was disappointed that they had not been warned of the potential side effects of their treatment.

▶ Do you think that people in the health service are working together to support you?

40 respondents felt that at least some of the healthcare professionals they were in contact with were working together. Several respondents in this group reported that referrals had come through or that GPs had been fed back to by hospitals. However, 12 respondents felt that services did not communicate with each other. For three of these, this linked to requests for support with social care needs and housing (damp) not being followed up. Others felt the professionals didn't follow up issues and one stated that their 'weak' English made communication with their GP difficult. 11 respondents didn't know whether professionals worked together, with the language barrier given as the reason in one of these cases as well.

▶ Do you feel that people in the health service involve you in discussions about your care?

45 respondents felt involved in their care. For many they felt involved because the professional had told them clearly how to manage their condition. Responses suggested that patients felt informed rather than involved, though a small number stated they were confident to say what they felt they needed. Others reported the benefit of speaking the same language as their doctor or being offered an interpreter. 14 respondents said that they didn't feel that they were given the chance or the time to talk. One respondent said his wife took care of this for him, as he felt unable.

▶ Do you feel able to talk to people in the health service about your care and support?

41 respondents said yes and 22 said no. Several emphasised that they can only talk when they have an appointment. Some felt that they could talk more to their GP than others, and some felt rushed at their GP appointment. Several felt confident to talk about their needs but didn't know whether this would result in their needs being met. Two noted that this depended on whether interpreters were booked and that this was not consistent.

Personal Health Budgets

'I would need information on the variety of treatments I could spend it on and how they would benefit me. Also where I could spend the money and what the limit would be. I would also need information on how the system would work and who would arrange or facilitate it. I cannot imagine that GPs would have time to do this. I also doubt whether they would be best placed to give me information about alternative treatments and the best place to get them.'

Respondent 10

All those who took part were provided with information on what a Personal Health Budget was, and how to ask for one if they decided they wanted one.

► **Have you ever heard of a Personal Health Budget?**

Hardly any respondents had heard of Personal Health Budgets. 58 of the 63 people we spoke to said they had not heard of them, nor had anyone in their care team ever spoken to them about one.

► **What information would you need to make a decision about whether to choose one?**

Respondents stated that they would need 'all the information', from criteria around who is eligible to what treatments would work for them to manage their conditions, how to spend and manage the money. Several felt they would need to attend a workshop on how the budgets worked so they could ask questions and get a sense of how it would all work. One noted that there didn't seem much value in them unless you felt 'mentally and physically capable'. There was some apprehension about managing the money,

'I do not want money, I just want the doctors and nurses to do what needs to be done properly. If I were to be given a personal health budget I wouldn't know what to spend it on and how to go about it. If Arachne could advise me on treatments that might help me and could help me to organise paying for them I would feel happier.' [Respondent 11]

► **Would you do anything differently if you had a Personal Health Budget?**

38 respondents said that if they had more choice, they would do things differently. Of these, 24 respondents suggested actions that could readily be supported. The most popular activity that people identified was taking part in physical activities. Going to local classes, the gym, or hiring a personal trainer were identified as activities respondents would take up if they had the resources. In some cases doing sport or going to the gym with someone else (to give them confidence) was mentioned. Some were interested in trying alternative therapies. One respondent said they would like to use a Personal Health Budget to help them travel somewhere sunny and increase their vitamin D levels. One suggested using it for transport to hospital. One said they would use it for special equipment (including a bed and gloves) to help with their particular condition. 16 respondents gave suggestions that were perhaps outside the scope of a Personal Health Budget, for example changing GP, private treatment, covering the cost of gluten free food, a dishwasher, re-decorating the flat, and access to carers. 18 respondents said they wouldn't do anything differently, six didn't know and one didn't answer.

Advantages

'Having a Personal Health Budget is an advantage, obviously.'

Respondent 7

Choice - you could choose different services, or different people.

'If I had a personal health budget I could have used the money for much better, more effective treatments instead of being sent to the physiotherapy which was a waste of time and money'.
[Respondent 15]

Better standard of living with the right care and support.

'If I get a [more] personal care I feel I would lead a decent life' [Respondent 44]
'[The] advantage would be being able to access equipment such as an oxygen machine, and the good impact on my health.' [Respondent 11]

Flexibility - you could arrange treatment and support for times that suit you.

'People have the freedom to take care of their own health, giving them independence in regards to that.' [Respondent 28]
'It will give me the flexibility to arrange a carer, and support the time and date I need.' [Respondent 57]

Language - you could employ support from people who speak your language.

'I can recruit [those] who speak my language so can be easy for me.' [Respondent 59]

Could employ family members who know you and your needs/ preferences.

'I can use my family to be my carer as they know what care and support I need.' [Respondent 61]

Convenience - direct payments happen automatically and don't need to be chased up.

'The advantage is the money is guaranteed in my account.' [Respondent 62]
'The advantage is I don't have to contact anyone regarding the payment, I don't have any worries to have the Personal Health Budget as direct payment I can manage properly.' [Respondent 60]

Concerns

‘Some of the disadvantages could be cost, waste, bureaucracy, fear of choosing the wrong therapy, responsibility of making right choices, unable to return to NHS if I change my mind about having a budget.’

Respondent 16

Quality of the service - and what you can do if the quality is not good.

‘Not all providers of therapies and treatments are the same, some are ineffective and a waste of money. I would be worried that I would use up my budget only to find that the treatment was unsuccessful. Also if I found after one or two sessions I wasn't happy with the treatment would it be very difficult to rearrange to go to an alternative provider?’ [Respondent 10]

Cost - would there be enough money for what you need, does the system have enough money?

‘It will be good for me to use it for private treatment. My worries would be if the Personal Health Budget Money would it be enough money to cover for private treatment.’ [Respondent 56]
‘I would need to know how long the budget would last and whether it would be continuing for the duration of my condition. For example if it was allocated for three months at a time and I would need to go through a lot of bureaucracy again to re-start it I would find it too stressful.’ [Respondent 18]

Managing the money and record keeping - could be problematic/ confusing/ stressful.

‘Might increase stress to hire and fire as well as finding the right items, costs and manage the budget.’ [Respondent 22]
‘My biggest concern is some people will get confused what the money is for and they will spend it on other things.’ [Respondent 31]

If you have debts or bills there is a temptation to spend the money on these priorities - you could end up in more debt.

‘People spending the money on their bills rather than their care and support.’ [Respondent 32]

Future changes in policy (leading to a reduction in support).

‘The worries are getting used to the Personal Health Budget payment and [it being] all over suddenly if stopped due to government cuts.’ [Respondent 63]

Lack of knowledge of services

‘A main worry about having a personal budget is that I would not know what was available and may not have enough information about what was best for my health condition’ [Respondent 11]

- ▶ Several respondents said that a third party handling the payment could be helpful.
- ▶ One respondent said language was a concern (in answer to this particular question).

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Copyright © Healthwatch Islington 2017
200a Pentonville Road, London N1 9JP
020 7832 5814
info@healthwatchislington.co.uk
www.healthwatchislington.co.uk
 [@hwislington](https://twitter.com/hwislington)