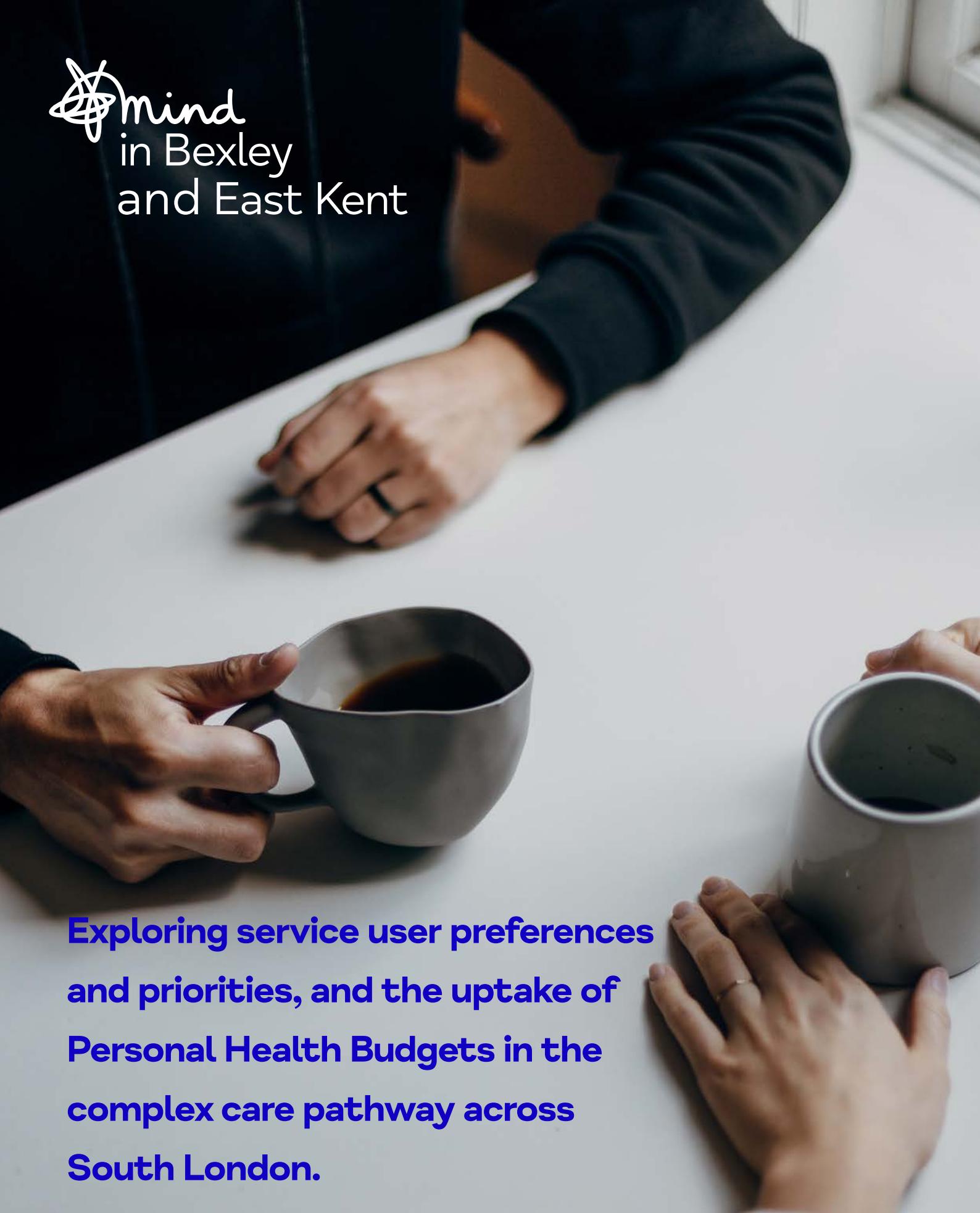




**mind**  
in Bexley  
and East Kent



**Exploring service user preferences  
and priorities, and the uptake of  
Personal Health Budgets in the  
complex care pathway across  
South London.**

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## **Introduction**

The NHS Long Term Plan published in January 2019 made a clear commitment to expand personalised care and Personal Health Budgets, with a specific expectation that these will be offered within mental health services as part of plans for up to 200,000 people to benefit by 2023/24. One of the key drivers behind Personal Health Budgets is giving people greater choice and control over the support they access to manage their mental health as this increases their prospects of recovery.

The South London Mental Health & Community Partnership (SLP) and South East London CCG Personalisation lead commissioned Mind in Bexley to develop a programme of engagement to draw on the expertise of people with lived experience of mental health difficulties regarding Personal Health Budgets.

The research provides valuable information for commissioners and service providers in designing a pathway to support the uptake of Personal Health Budgets across the SLP and thereby increasing recovery outcomes, choice and control.

## **Summary of Findings**

Mind in Bexley engaged with 64 service users with placements in inpatient rehabilitation, residential / nursing care or supported accommodation across South London. Participants were from a range of genders, ages and ethnicity. Engagement was time intensive as it needed to be in person rather than online due to needing to build trust and the depth of information covered

The importance of listening to and engaging with users was highlighted by many individuals in the study.

Service users and staff lacked knowledge about Personal Health Budgets. None of the participants had any clear knowledge or understanding of what Personal Health Budgets are, what the eligibility criteria is and how to access one. Only 5% per cent of the health professionals who acted as brokers to access individuals for this study had ever heard of Personal Health Budgets.

Personal Health Budgets were positively viewed by the majority of respondents as a concept and principle.

Of those interviewed 64% said after hearing about the concept that they would be keen to have one. Participants valued being asked what they thought would most help them to be as happy and healthy as possible and that a Personal Health Budget could give them the choice to access this support.

37 participants had a clear idea of what they would like to access if they had a Personal Health Budget. These included travel, education and training, physical activities, personal assistants, alternative therapies, equipment, pets and hobbies.

There were levels of caution and doubt with regard to how effectively it would be delivered in practice. Concerns included worries and delays over the administrative process, the burden of managing the budget and the disappointment of being turned down.

## Personal Health Budgets: An overview

Personal budgets were first developed in social care for people with physical disabilities, and have been widened to Personal Health Budgets for other groups who have long term conditions, including people using mental health services (Alakeson, 2007a, b)

**Glossary of personalised budgets** A personal health budget is for NHS healthcare and support needs. A personal budget is for social care and support needs. An integrated personal budget is for both healthcare and support needs and social care needs. A direct payment is one way of managing these budgets when a client receives the money directly to buy the agreed care and support rather than the council or the NHS arranging it for them.

Interestingly, whilst the uptake of Personal Health Budgets has been high in people with physical disabilities and learning disabilities, it has been less utilised by people who use mental health services.

Personal Health Budgets are a way of offering individuals with disabilities and long-term conditions greater choice and control in how the NHS supports them in improving their health and managing their care. Personal Health Budgets allow service users to work with a team of healthcare professionals to choose the health and wellbeing outcomes they want to achieve and create a care strategy to help achieve those outcomes. This includes establishing a budget for support, creating their Personal Health Budget care plans and choosing how their care and money is handled and by whom. At the heart of the Personal Health Budget is the patient's care plan. Under this plan, the patient should be given help to decide their health and wellbeing goals, and to set out how the budget should best be spent. Budget holders are theoretically able to use their budget for a wide range of things to help them meet their goals including, for example, complementary therapies, personal care, and one-off items such as a computer or a Wii fit. The budgets cannot be used to pay for emergency care or care normally received from a GP. Neither can they be spent on gambling, debt repayment, alcohol or tobacco, or anything unlawful.



## Methods

All interviews were undertaken digitally (on line Teams) (N=8) or in people's place of residence and followed a conversation approach where individuals were encouraged to freely discuss issues they felt were important to them. The interviewer (NS) took care to be sensitive to topics initiated by the narrators and to allow the interview to proceed in as naturalistic manner as possible. Interviews were written verbatim or audio recorded with participants' written consent and the recordings and transcripts were transcribed for a thematic analysis. The research team considered key ethical issues and dilemmas including the complex issues of insider and outsider status, lack of familiarity with the research process, issues of informed consent and safeguarding anonymity; these issues were addressed in the invitation to participate, design of the interviews and process of data collection.

Interviews varied in duration but lasted on average for 50 minutes and all interviews were undertaken at a time which was convenient to participants. No interviews were conducted with a family member/ carer present or responding on behalf of a care recipient.

## Recruitment and engagement

A list of placements was originally contacted by the Complex Care Pathway Team and all staff were sent a letter and study information sheet, inviting service users to participate in the study. Service users' views were incorporated in the design of information sheets and consent forms. Data was extracted using a semi-structured topic guide as a framework.

## Limitations of the study

For this study, non-probability sampling was undertaken which refers to situations where the research cannot or does not sample the whole population and therefore cannot claim representativeness. As a result, such sampling techniques severely limit the potential to generalise from the findings of the sample to the wider population.

It is necessary to acknowledge the limitations of this study. A total of 64 interviews were undertaken between April and July 2021 and it could be contended that the information gained from such a small sample cannot be generalised to the wider population. However, analysing the specificity of different individuals is seen as significant, especially for participants involved, and the views and opinions will allow for some level of exploration of the impact of Personal Health Budgets and mental health for the wider forced population. It will also help inform the SLP in how to develop processes to support uptake.

## Personal Health Budgets: What's in a name

Personalisation places people at the heart of the assessment and discussions about how they would like their services delivered, ensuring they have as much choice and control over the shape of their support as possible. It enables the provision of services tailored for each individual rather than providing a one-size-fits-all-package. The introduction of Personal Health Budgets is one element of a personalised approach to improving outcomes for those eligible. The diagram below illustrates this personalised care.



66 Why is it called that? It sounds like it's a managing your budget course or something like that. Shouldn't it be a health supplement package or something (Residential, Male) 99

One participant although he had never heard of Personal Health Budgets stated he had

66 heard of other payments made to people to have support under something called payments direct or something like that – is that it? (Residential, Male) 99

Some stated confusion over the name and raised concerns about the link with welfare benefits. One participant said

66 Would they take the money out of my benefits...how would you pay it back and would it be the same amount" whilst another said "they give it to you in one hand and then take it away from the other. (Both Inpatient Rehab, Male) 99



## Barriers: Lack of Knowledge

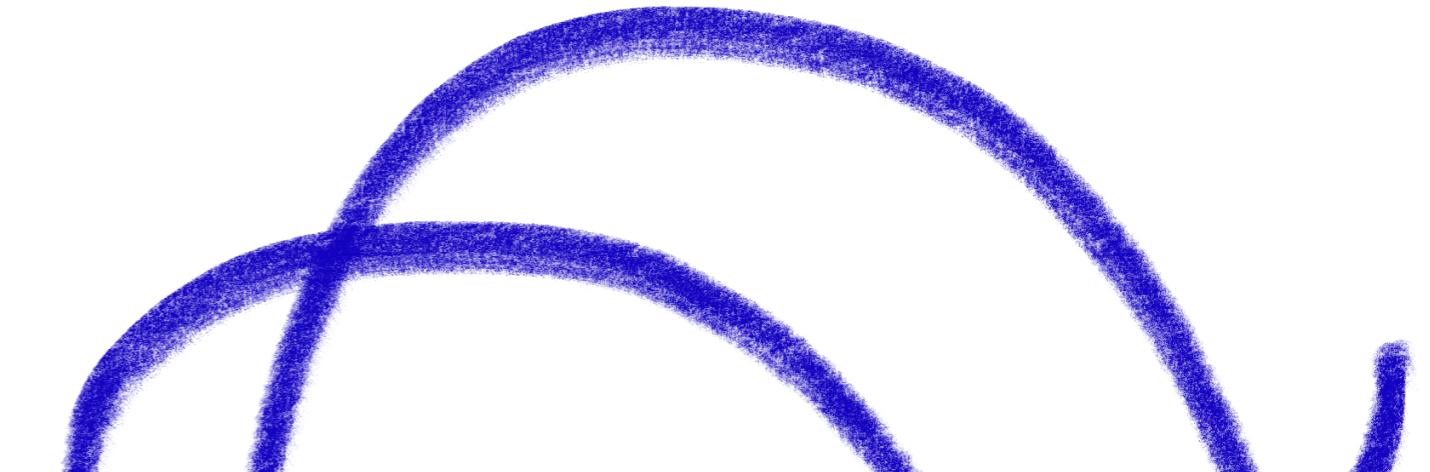
This study identified a number of barriers which meant that although people with mental health problems are among the groups most likely to potentially benefit from access to a Personal Health Budget (MIND, 2012), none of the participants involved in this study had any clear knowledge or understanding of what Personal Health Budgets are, what the eligibility criteria is and how to access one. Our research also highlighted that 95% per cent of the health professionals involved who acted as brokers to access individuals for this study had never heard of Personal Health Budgets either.

**I've no idea what it is. I certainly haven't been told about it. Who gets it and how much is it? (Health Care Worker)**

Participants had therefore no knowledge of the assessment process or their rights to access one. One of the main reasons given for this was the lack of information about Personal Health Budgets. This lack of knowledge had a knock-on effect upon the ability of service users to decide on whether they would take up the opportunity if it was accessible to them. Importantly service providers also acknowledged and confirmed the lack of information and awareness in the sector is a significant factor on Personal Health Budget take up.

**Well let's put it this way if we don't know about them and how they work and who is eligible how then are patients supposed to know. We need to know about these things.**

A number of service providers and the health professionals who acted as brokers in the study stated that they were very aware of the barrier posed by this lack of information. They acknowledged that take-up depended upon the knowledge imparted by care coordinators due to a lack of knowledge in the system to promote them.



## Barriers: Lack of Knowledge

Personal Health Budgets aim to give individuals more choice about the services and support they receive, by giving them greater control over money that is spent on their health care (but excluding primary and emergency care). The recommended process for receiving a Personal Health Budget is that, after an assessment of needs, an individual is told how much money is available to them and draws up plans for using the budget in ways that are intended to benefit their health and well-being. This research wanted to explore how Personal Health Budgets could work in mental health. We were keen to hear what people with mental health problems want from services and support, and what role Personal Health Budgets could play in improving both their experience of care and their mental health and wellbeing needs.

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**So what would happen if I agreed something and filled out all these forms and then they turned it down? That would make you feel shit really. I'd be looking forward and then bang no. That would wind me up (Residential, Male)**

## Potential take up in principle

Respondents mostly agreed that in principle, the concept of Personal Health Budgets was something with which they agreed and that as the basis for the delivery of support and/or services, it was the right way forward. Of those interviewed 64% said after hearing about the concept that they would be keen to have one. While Personal Health Budgets were positively viewed by the majority of respondents as a concept and principle, there were levels of caution and doubt with regard to how effectively it would be delivered in practice.

## Spending a Personal Health Budget and improving wellbeing

Using a Personal Health Budget to improve wellbeing is expressed clearly by a participant who would choose to get fitter physically

**I would use a (personal health) budget to help me access a gym and maybe a trainer to encourage me to do regular exercise, maybe 3 times a week and that would help we lose weight. I'd definitely feel better about myself then and it would definitely help it terms of motivation and I'd be encouraged to do more things I think. You know if you start to look good you feel better...you feel more confident about yourself and I'd start to look after myself better. I'd take more of an interest in my appearance as well and I'd even start to think about my diet and what I eat and my lifestyle in general**

One of the key drivers behind Personal Health Budgets is giving people greater choice and control over the support they access to manage their mental health and recovery. Giving service users more say over their own care can help to target treatment to meet their individual and specific needs in a way that fits in with their own lives, increasing their prospects of recovery. By putting funds in the hands of people actually using services, Personal Health Budgets can enable them to access a range of support and activities within or outside of existing commissioned NHS services, including those provided by voluntary organisations, as well as mainstream activities within their own community.

## **Spending a Personal Health Budget and improving wellbeing**

Although our interviewees were initially sceptical that such extensive choice would ever be available through a Personal Health Budget, as this had not been their previous experience of services, once we explained the idea in more detail, most people (64%) were positive and had ideas about what they might do differently if they had access to a Personal Health Budget.

Respondents were interested in a range of services or activities to meet their mental health needs. People were interested in help with accessing education courses, help with purchasing IT equipment (laptop, phone, tablet), the costs of travel and transport, having access to a gym and a personal trainer was popular and help with music related activities was also mentioned. Personal Health Budgets could be a way to drive parity of access to these types of approaches, which are recognised as beneficial to wellbeing, for people with mental health problems. Interestingly many participants included a supportive signposting or navigation function or assistance with accessing the scheme, managing money, budgeting and accounting and accessing required services:

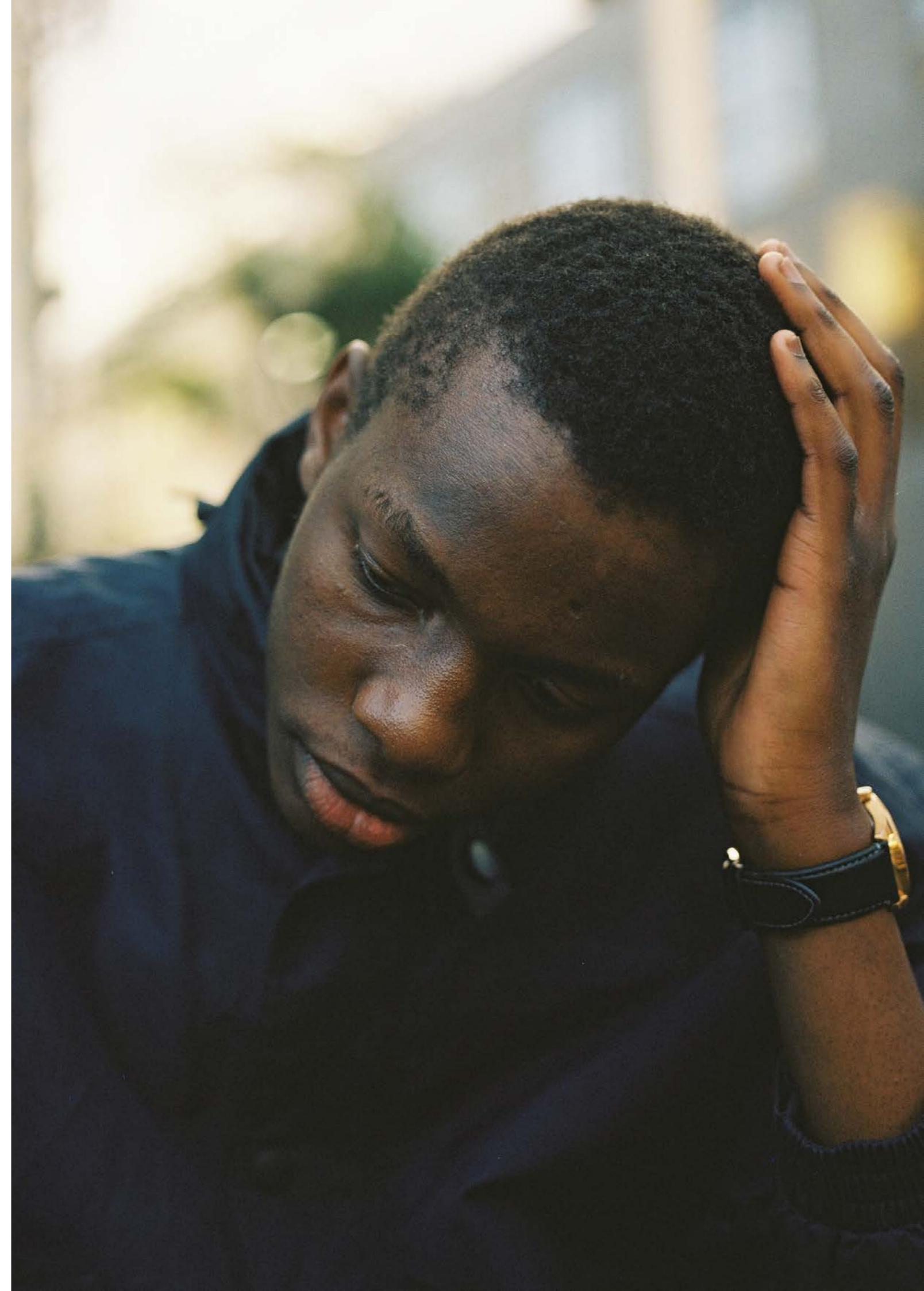
**I'm definitely interested in getting one of these but I would want some help with managing it and the finances part of it and help with doing it. I want help with a laptop to access a course but I'd need some help with managing it all**

It is clear that some of the items/activities requested might not even require a Personal Health Budget as they may be obtained via a different route that needs to be explored further. For example:

- Some travel might be available with a Freedom Pass.
- Some GPs are able to prescribe gym memberships.

Twenty-three (36%) of the service users with did not wish to apply for a Personal Health Budget or would not answer the questions. Those who did answer tended to remain confused by the word “budget” as highlighted elsewhere.

**I do not want or need any help with budgets and finances. I get enough money already  
I do not want to explore this, thank you. I have everything I need already**





Participants generally said they did not want to discuss their finances, had already “had enough people poking around” and would not engage with the concept.

Four people (6.25%) struggled to think of something they would use a budget for and indicated that they would need more time to think about what is important to them and what choices they would make.

**I'm struggling to think now of things. I'd want to think over it and discuss it with others and the staff here. I'm really not sure to be honest, I wouldn't want to get it wrong that's for certain**

This would suggest that the Personal Health Budget agenda needs to be approached with individuals as early in the Recovery journey as possible.

## Travel

The two people (3.1%) who asked for travel costs to be paid have very different reasons for requesting this. One of them enjoys travelling on public transport and finds it therapeutic:

**It would help me get me out of the house. It would ease my conscience knowing that I have money on my card. It would give me something to do and I think It would also stop me from being hyperactive. Yes I'd find it a very therapeutic thing to do**

Whereas the other person who wanted travel costs wanted to specifically visit family members:

**When I leave here, I will need their support (Family) even more. Especially my sister. I only have them here. My health depends on seeing them properly.**

One individual told us that her only concern when she is discharged is that she will not be able to get to have her depot injections. She explained to us that she had previously become unwell because she had not been able to get to her appointments with her community team as she could not afford the cabs to get there. This had resulted in a hospital admission.

**I need my injection (depot) but they expect me to travel a long way for it. I will need to get a cab and cannot afford it so I would use a budget for taxis. Without it, I will get ill again**

## **Education**

### **College courses**

Many recipients interviewed preferred Personal Health Budgets to be spent across a range of education related areas. This included funding college courses which are currently unaffordable.

**It would give the day some structure. I would have to be organised and I would meet new people. I would feel better about myself. It would help with depression and give me something to live for. It might all reduce my anxiety levels**

## **Language Support**

One individual stated he would spend a Personal Health Budget on learning English so that should his health deteriorate he would be in a better position to communicate his needs to professionals. ESOL learners have the additional stress of perhaps not fully understanding procedures and processes that have caused them to be detained under the Mental Health Act and that exist in an in-patient environment.

**If I speak English, I will better be able to say when I am ill. I stayed in hospital just because my English is not clear**

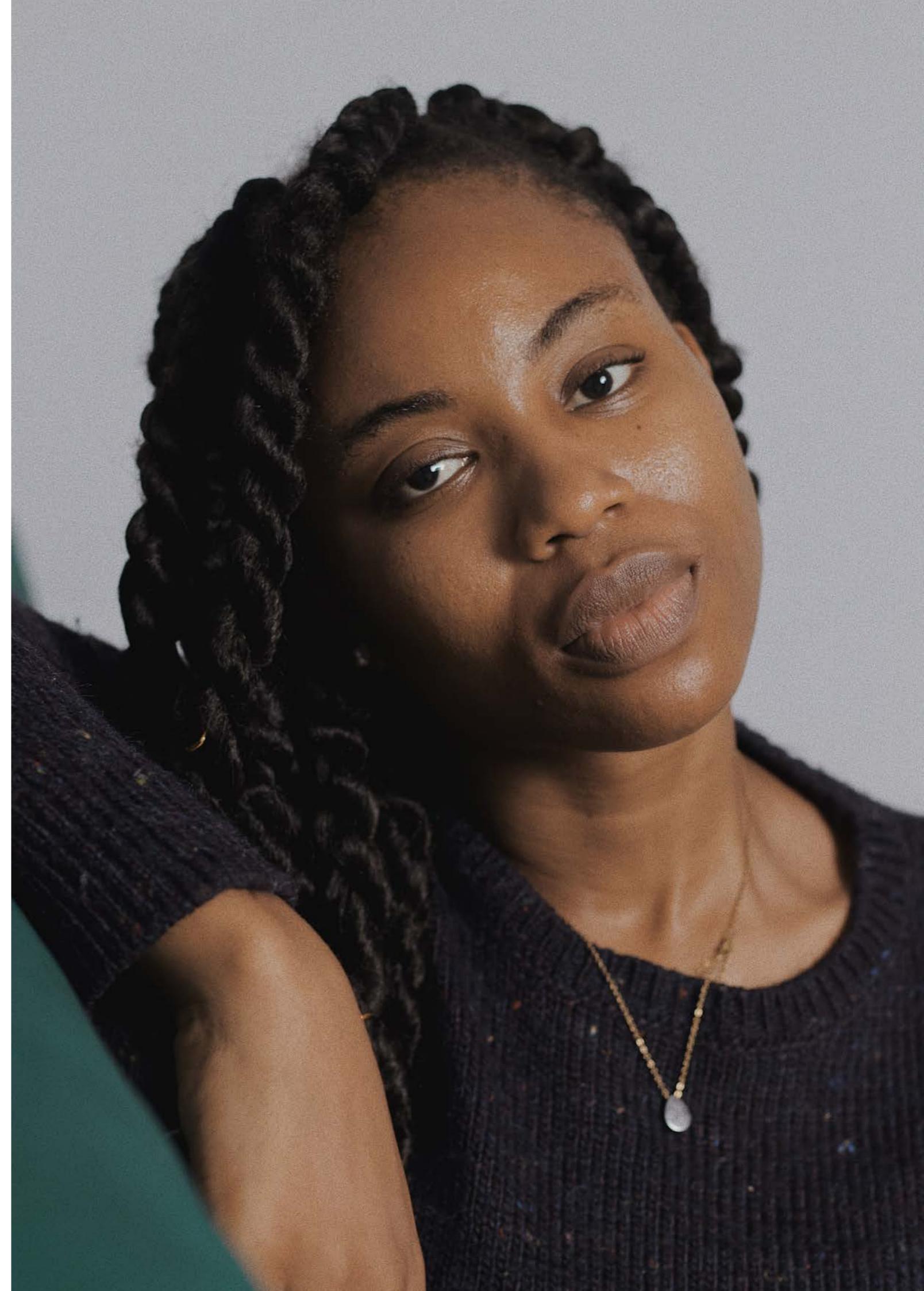
## **Equipment for studies, courses, job searches and online therapies**

Seven (11%) people asked for laptops/iPads to help with their study and or access on-line therapy:

**I could do more courses on-line and CBT stuff, trying to do that on a phone is impossible**

**It would help with job searches and I would be more focused as its easier to use**

**I could progress more, from courses into work**





In the past couple decades and particularly since lockdown, one-to-one laptop/IT programs have spread widely. This technology can be used for studies, engaging with teachers or other students, accessing courses which would not be otherwise and developing IT and other skills.

**I could research more, engage with the course and students better and develop friendships and it would no doubt benefit me long term**

## Equipment for social contact

One individual was interested in purchasing a mobile phone through a Personal Health Budget. The individual does not currently have one due to affordability and would like one to stay in contact with friends and family

**I really need one so I could stay in contact with people and it would help reduce isolation**

## Physical Health

### Gym membership or personal trainer

Nine participants (14.7%) informed us they would like either gym membership or a personal trainer and referred to how being physically well would impact on their mental health. Individuals spoke about having “got into going to the gym” whilst in hospital which were free of charge and are now not able to afford going post hospital discharge:

**They wouldn't take my tablets away so why do they think its ok to take the gym away. It's the one thing I love doing. It was part of my recovery**

**They got me into something that I cannot now afford to do. I really miss it and that's what I would spend my money on  
Others spoke of the benefits they feel it would have in relation to their mental health**

**It releases endorphins you know which is good for reducing my stress. It gives me a feelgood factor which I don't get from anything else**

**I would need someone to take me to those places volunteering, cooking course, horse riding and other things and stay with me. I did these things before and loved them. They made me happy. Getting out and about would make a big difference to me. I could socialise more which might help my social anxiety. It would help me become more confident and would give me some freedom I need to get out of the house but my paranoia won't let me so I need someone there to be with me, travel with, keep me calm and get me back safe**

## Pets

One participant spoke of using a budget to buy a dog. A pet can be a great source of comfort and motivation. It is well known that caring for a pet can help our mental health in many ways, including:

- increasing physical activity. Dog owners are likely to take their pet out every day for a walk or run.
- providing companionship. Pets can give you a sense of security and someone to share the day with. Caring for them can help you feel wanted and needed
- the companionship of a pet can help to ease your anxiety
- boosting self-confidence. Pets can be great listeners, offer unconditional love and won't criticise you. This can help your self-confidence, especially if you feel isolated or misunderstood
- helping you meet new people. Dog owners often stop and chat to each other on walks. But other pets can be a way to meet people too: in pet shops, training classes or online groups, for example
- adding structure to your day. Having to feed, exercise and care for a pet can help you keep to a daily routine, which can help you feel more grounded and focused. It can give your day purpose and a sense of achievement.

**A dog, partly for the company but also you have to walk the dog... so you have to go outside. If I am having a day where I just want to curl up into a ball and hibernate for three weeks, the dog needs a walk**



# Key Recommendations

- Ensure staff have the knowledge and skills to communicate what a Personal Health Budget is and explore with the individual how this could help them
- Co-produce information about Personal Health Budgets with people who use services and which demonstrate the possibility of positive outcomes from Personal Health Budgets including stories of how people have benefited.
- Provide training for all relevant parties including statutory, voluntary, community and faith sectors to ensure they fully understand Personal Health Budgets and the level of Personal Health Budget support to which clients are entitled.
- Employ community organisations and individuals with lived experience to be involved in the delivery of education and training programmes to communities and service users in order to improve take up.
- Ensure equal opportunities for BAME individuals by providing a culturally sensitive approach with access to interpreters and provision of Personal Health Budget information in a range of languages.

- Work alongside voluntary and community sectors to build a resource of what may be available and ensure mental health staff are aware of what is available.
- Ensure advocacy and mentoring, befriending or peer support services are funded and offered to users to support them to access and use Personal Health Budgets
- Ensure equitable and fast access to Personal Health Budgets through establishing clear eligibility criteria, pathways, systems, budget holders and decision-making processes so that delays in decisions and payments are avoided.
- Establish an involvement strategy and ensure evaluation, consultation and planning mechanisms are in place to incorporate user and other stakeholder feedback into ongoing improvement of how Personal Health Budgets are provided.
- Fund a formal evaluation of the progress of Personal Health Budget implementation in July 2023 which includes analysis of client use of budgets, client feedback, outcome measures, ease or difficulty of accessing budgets, reasons budgets have been declined and how far the joint action plan has been achieved.

## Glossary

A personal health budget is for NHS healthcare and support needs.

A personal budget is for social care and support needs.

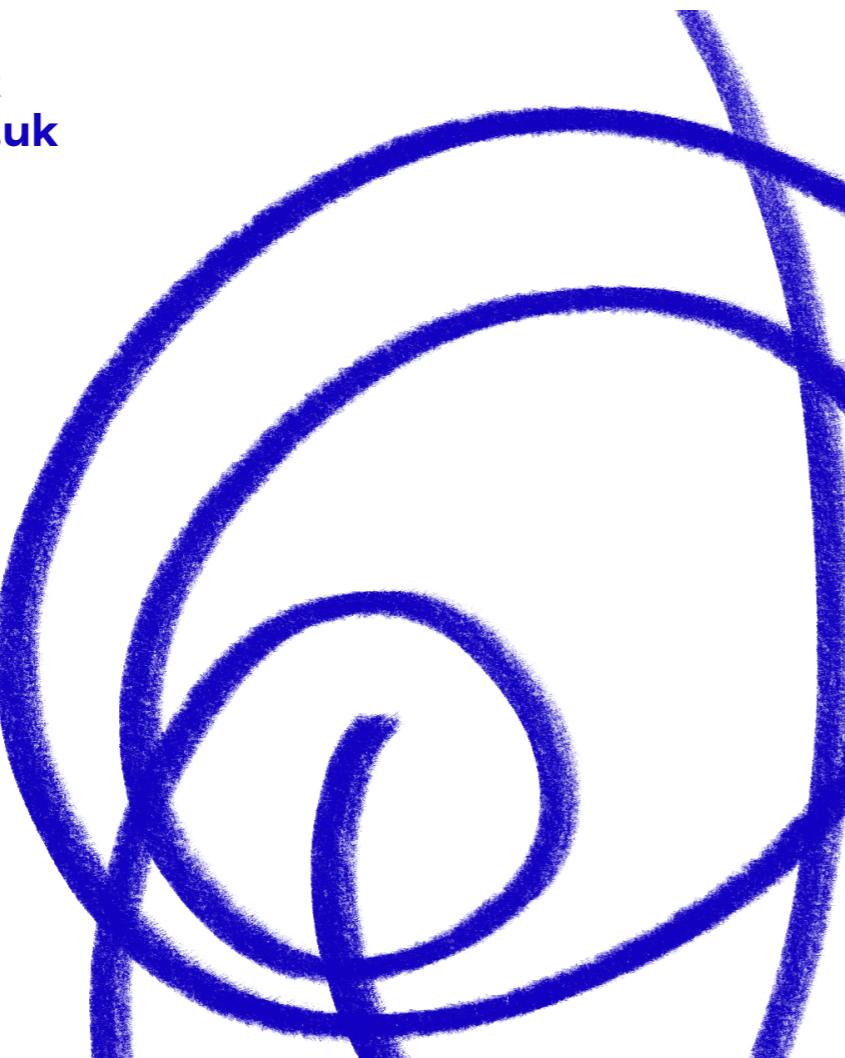
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## Acknowledgments

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A large, faint, stylized brain icon is visible in the background, composed of several overlapping, textured, light-blue shapes.

**Join the fight for  
better mental health!**

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