

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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EXECUTIVE SUMMARY

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 Clinical Commissioning Group (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.

Engagement

The Mind research team 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.

KEY FINDINGS

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

We found that 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.



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.

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. It's 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.

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Introduction

The South London Mental Health & Community Partnership (SLP) is developing the complex care pathway. People using this pathway have mental health needs alongside needs requiring inpatient rehabilitation, residential/nursing care and/or supported living. The pathway is being developed to the principles of personalisation whereby;

- The person's goals and wishes are prioritized
- Care and support is driven by the person being supported
- Maximum choice is offered

To make sure that any improvements and developments come from the needs and preferences of people who use the services, the SLP and SEL Clinical Commissioning Group (CCG) Personalisation lead commissioned Mind in Bexley to develop a time limited programme of engagement. A group of local commissioners, CCG leads and staff from the South London Partnership and South London & Maudsley MH Trust worked with the author (DP) to plan the research. Using the principles of co-production, the team wanted to draw on the expertise of people with lived experience (of mental health difficulties) at every stage of the project.

Mind have extensive research and daily work experience of supporting and researching those in high support placement settings including Chapel Hill, Crayford, Dartford and the specialist forensic mental health unit at the Bracton Centre. From our experience it is crucial when undertaking such research that residents are supported and encouraged to have a voice so that researchers represent their interests and enable participation in decision making.

Mind in Bexley's Chief executive Dr David Palmer was the "lived experience project lead" leading and supporting the project and worked closely with other members of the research team which included the Mind advocate Nicki Smith and recovery college facilitator Dina Phillips. All of the research team are mental health survivors. They have seen first-hand the devastation mental health problems can cause and the difference early intervention and support can make and this experience and expertise was brought to this project.

Our aim was to undertake a research project which details the narratives of 60-70 conversations with people using inpatient rehabilitation, residential / nursing care and supported accommodation, to better understand individual stories emerging about care and support plans, peoples changing perspectives, their unique care needs and explore ideas through Personal Health Budgets that will help rebuild and aid their recovery as part of their overall care package. All interviews initially intended to be undertaken remotely via zoom, teams, or telephone. However, this proved to be challenging and we undertook face to face interviews with the majority of participants. Face to face interviews were in various locations whilst adhering to social distancing and Covid regulations. This research developed the work already undertaken by the Personal Health Budget steering group by capturing the views of recipients themselves.

The aim of the study was to investigate the feelings and experiences of recipients using qualitative oral history research methods. Significantly this study has important educational benefits, giving the recipients the opportunity to speak out about their experiences and explore Personal Health Budgets thereby generating awareness in public attitudes towards the complex issues of mental health and Personal Health Budgets. Individual 'voices' narrate stories, express opinion, and so contribute to the ongoing discourse within health and social care. The equitable nature of oral history, which values individual subjective knowledge and allows them to give validity in the debate and analysis. In this report, the qualitative data provide in-depth insights into the phenomena under consideration and allow themes to emerge. These themes are analysed more extensively, and, based on this analysis, recommendations are drawn for policy and practice.

We are designing a booklet which represents the thematic categories and recommendations obtained from the interviews. Findings from this report will also be disseminated through a visual exhibition which will be made available throughout the partnership to work to generate awareness in public attitudes towards Personal Health Budgets and the complex issues raised. The results of the study will be presented to the South London Mental Health & Community Partnership and the Executive Group. A summary of the results will be made publicly available via the Mind website, and further arrangements for the dissemination of the findings will be discussed with the funders.

It is hoped that this research will provide valuable information for commissioners and service providers in designing a pathway to support the uptake of Personal Health Budgets and increase recovery outcomes, choice and control.

Personal Health budgets: An overview

The Government has committed to expanding the use of Personal Health Budgets for health service users following the evaluation of the pilot programme which ran from 2009-2012. This is part of a wider 'personalisation' agenda, which has become a central theme in the reform of health and social care in England, and also features increasingly prominently in the policies of other UK governments (DoH 2009,2010, Jones et al 2010), in addition to governments of many other developed countries around the world. Personalisation is defined by central government as "the process by which services are tailored to the needs and preferences of citizens. The overall vision is that the state should empower citizens to shape their own lives and the services they receive" (Cabinet Office 2007, 33). There are a number of drivers behind the desire to 'personalise' health care in England: 1) it is expected that personalisation is a route towards better integration of health and social care services, through its focus on the whole person; 2) personalisation might help to improve people's management of long term conditions through a strategic shift towards early intervention and prevention; 3) personalisation will encourage the provision of services that will allow people to be maintained at home; and 4) personalisation will improve patient experience and outcomes through promoting choice, control and flexibility

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 (Curry and Ham, 2010; Coyle, 2011). 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 (DoH 2009,2010,2016). 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 (DoH 2009, 2010, 2016). Neither can they be spent on gambling, debt repayment, alcohol or tobacco, or anything unlawful.

A 2014 National Personal Health Budget review found that Personal Health Budgets had particularly positive impacts for those with mental health conditions (Jones et al 2017). The pilot programme included more than 20 areas that offered Personal Health Budgets for mental health and found that the use of Personal Health Budgets resulted in significant improvement of people's quality of life and wellbeing and were cost effective. These areas worked with a range of different populations, from older people with dementia to young people in early intervention services, and with a range of types and size of budget.

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 they will be offered within mental health services as part of plans for up to 200,000 people to benefit by 2023/24 (NHS. The NHS long term plan. 2019. <https://www.longtermplan.nhs.uk/>). Following an announcement in February 2019, people who are eligible for section 117 aftercare under the Mental Health Act have a legal right to a Personal Health Budget from 2 December 2019. (<https://www.england.nhs.uk/publication/guidance-on-the-legal-rights-to-have-personal-health-budgets-and-personal-wheelchair-budgets/>) After-care services under section 117 of the Mental Health Act covers the provision or arrangement of help and support for people who have been detained in hospital under sections 3, 37, 45A, 47 or 48 of the Mental Health Act 1983, when they leave hospital. For this group, a Personal Health Budget may be considered whenever planning is taking place for section 117 mental health after-care needs during an admission to hospital, or at any assessment held to review the person's section 117 after-care package of support in the community.

Personal Health budgets and the recovery model

Recovery and personalisation see people who use services as “whole people in their whole context” (Brewis and Fitzgerald, 2010). This means recognising that alongside the diagnoses, deficits and dysfunctions individuals may have, they also have strengths, skills and assets to contribute (Perkins and Slade, 2012). They have likes and dislikes, preferences, tastes and values. Everyone is more than a ‘mental patient’ and occupies multiple roles as, for example, parent, sibling, child, employee and carer (Duffy, 2010). An individual’s social context also brings with it strengths and possibilities for enhanced recovery (Duffy, 2010). The support of family members, social networks or having a valued role in the community can all provide the hope that drives individual recovery.

Recognising individuals as whole people and harnessing their strengths, preferences and motivations will strengthen the possibility of recovery. Personal Health Budgets are closely aligned to one of the central strands of service transformation in mental health: recovery. Adopting a recovery focused approach to mental health services means moving beyond symptom and risk management to support people to re-establish a meaningful life for themselves with their mental health condition. Recovery requires services to look beyond treatment to consider wider issues such as housing, employment and family relationships. As a highly personal journey, recovery depends on services being able to develop individually tailored approaches.

Personal Health Budgets are a tool to support more recovery focused services by allowing individuals to define their own outcomes and design their own packages of care and support. For Personal Health Budgets to be effective, planning must focus on a person’s whole life – what is good, what could be better, what matters most to them and what are their goals and aspirations. The planning that the mental health system does for and with individuals should, therefore, be seen as only one contribution to self-management. For people who are subject to the Care Programme Approach (CPA), that care plan can be integrated into a single plan to support recovery that the person manages as part of their own self-management plan, Personal Recovery Plan or ‘Wellness Recovery Action Plan’



Methodology

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.

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 (Jeffri, 2004; Denzin and Lincoln, 1994). 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 (Jacobsen and Landau, 2003). 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.

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.

Engagement process with care homes, supported housing and rehab units.

In February 2021, Mind in Bexley started the process of contacting a number of sites housing mental health service users in the South East London Partnership with focus on the five boroughs which are part of the SLP footprint. The managers of these units had already been contacted by members of the Complex Care Team who had explained the Personal Health Budget Research and the process to them. The original plan had been for conversations with service users to take place digitally online via Teams.

The Covid-19 pandemic has led to an inevitable surge in the use of digital technologies to undertake qualitative research due to the social distancing norms and the nationwide and regional lockdowns. With the spread of the pandemic, all areas in the South East London partnership had implemented lockdowns, shutting down activities that require human gathering and interactions. This had resulted in participants taking to the internet and internet-based services to communicate with the researcher. Many research issues arose with regard to on line research, which included aspects of trust, communication effectiveness, and collaboration. Although remote research can be highly effective but it has limitations. For example:

- It became harder to recruit participants to take part
- It can be harder to learn about the context in which users are based

It soon became clear that, for a number of reasons, this process was not working:

- Trying to contact the managers was time consuming and they were frequently unavailable.
- Emails were not always responded to.
- Once contact was made, it was difficult for them to be able to predict when service users would be free to engage.
- Interviews via Teams also required a member of staff to be present on the day in order to set up the laptop and start the meeting which was very time-consuming.
- Having made the appointments, the interviews were frequently without notice cancelled on the day.
- When meetings were successfully facilitated, the service users were essentially being asked to engage with a person who they had never met before via technology and many were understandably uncomfortable with this.
- Occasionally, Wi-Fi issues resulted in meetings not taking place.

In April 2021, the lockdown rules in the UK changed and this resulted in a decision for the researchers to visit the units in person in order to meet with service users which proved very successful. Uptake was also encouraged through a video made by Mind in Bexley. The research team complied with the relevant risk and health and safety procedures.

These included:

- Up to date and thorough risk assessments.
- Considering how vulnerable interviewees are (including for example their age, ethnicity and any relevant health conditions).
- Provided with personal protective equipment (PPE) and hand sanitiser.
- Considering travel to and from research sessions and any ways that risk can be reduced, for example allowing researchers to drive their own vehicles rather than using public transport.
- Having guidance for researchers so they can make real-time decisions about whether where they are Covid-secure and allow them to end a session if they feel they are being exposed to too much risk.
- Having clear, easy processes to follow after fieldwork sessions, including cleaning equipment.
- Clear reporting procedures.

By the end of June 2021, we engaged with 64 service users, most of whom (86%) went on to engage fully with the research process and questionnaire. The figures used in the database does include those who spent time with us but who then decided to not complete the questionnaire. These are people who we actually met with and who engaged up to the point where they had to decide whether or not to complete the questionnaire. They were made aware of who we are, what the research was for, details about Personal Health Budgets but they ultimately decided to not take part. These people make up 14% of the total numbers we met with.

We visited 17 different sites, some of them on multiple occasions in order to capture as many people as possible. We interviewed people at 5 different homes online via Teams Meetings/Zoom and later visited 2 of those places to interview more people.

Consumer Involvement: Focus Groups

A draft version of the findings was sent to various parties including some participants who were involved in the study and they were invited to provide comments. Service users who participated in the research were invited to take part in a consultation event where a summary of the findings of the report were discussed as part of a focus group. Six service users attended focus groups in mid-July over two settings and participated in a discussion on the findings. Responses and contributions from both consultations were treated as data and incorporated in to the final report.

Data Analysis

Data analysis followed the 'Framework' approach (Ritchie and Spencer, 1994) a content analysis technique widely used in qualitative research. Each of the transcripts was read and re-read by the author, following which a coded framework was devised. Thematic categories were applied to each transcript and then 'charted', a process by which key points of each data were summarised and documented on a spreadsheet matrix. Thus, a set of categories were obtained which described the main themes arising from the interviews. The author (DP) worked collaboratively with colleagues from Mind and with Canterbury Christ Church University who 'pair coded' the data. This pairing forced a level of communication and understanding of the data that may not be otherwise achieved.

The findings and discussion sections have been merged due to the nature of the research findings. The quantitative findings are supported by qualitative and informative research with individual 'voices' narrating stories, expressing opinion, and therefore contributing to the on-going discourse within the field of Personal Health Budgets and mental health studies in general.

Demographic Profile

Sixty-four (n=64) individuals agreed to participate in the study. Seven agreed to have their interviews recorded with Microsoft Teams. Of the 64 who initially agreed to be interviewed, 13 answered some questions but declined to complete the full interview, leaving fifty-one (n=51) who participated fully. Reasons cited for not completing the interview included having little or no interest in Personal Health Budgets, being too unwell, confusion about the aims of the study and/or having other priorities. One individual stated he didn't have trust in the research process and despite assurances made by the interviewer (NS) was concerned about being able to remain anonymous and declined to participate.



Gender

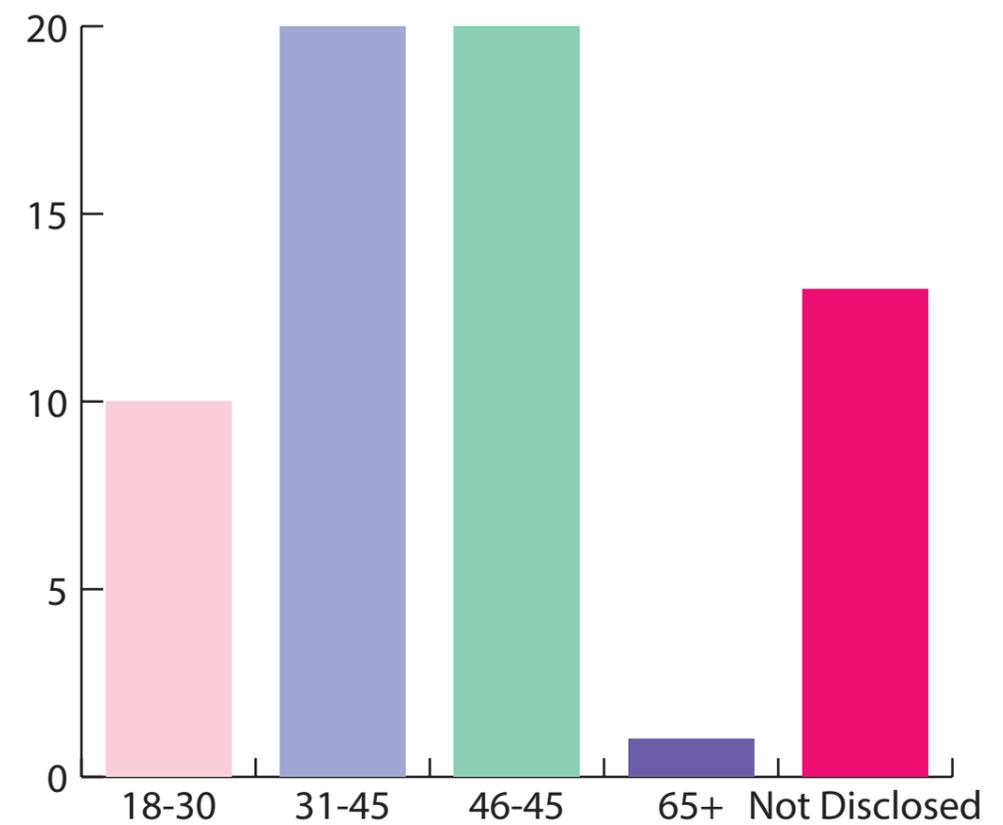
Of the 51 individuals who took part in the evaluation, the majority were male (71%, n=35).

Gender	Number
Female	19
Male	45
Total	64

Ages

Ages ranged from 21 to 67 years with thirteen (N=13) individuals refusing to state their age.

Age	Number
18 - 30	10
31 - 45	20
46 - 65	20
65+	1
Not disclosed	13
Total	64

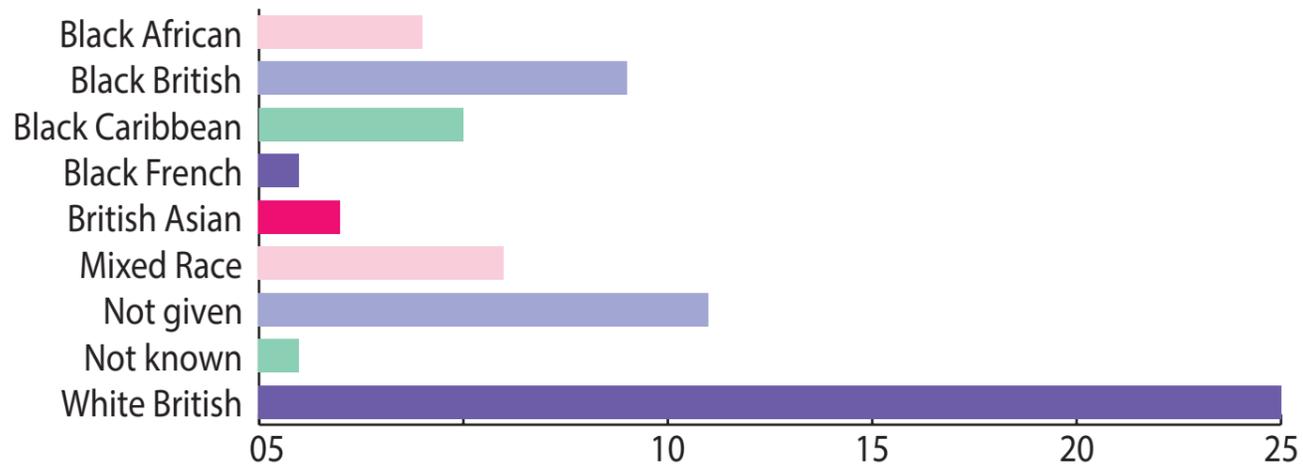


Ethnicity

In terms of ethnicity, twenty-five (n=25) participants defined themselves as White British, five (n=5) stated Black Caribbean, nine (n=9) declared themselves as Black British, six (n=6) identified themselves as mixed heritage and two (n=2) people stated British Asian, whilst one person identified themselves as Black French.

Eleven (n=11) declined to state their ethnicity and one did not know their ethnicity.

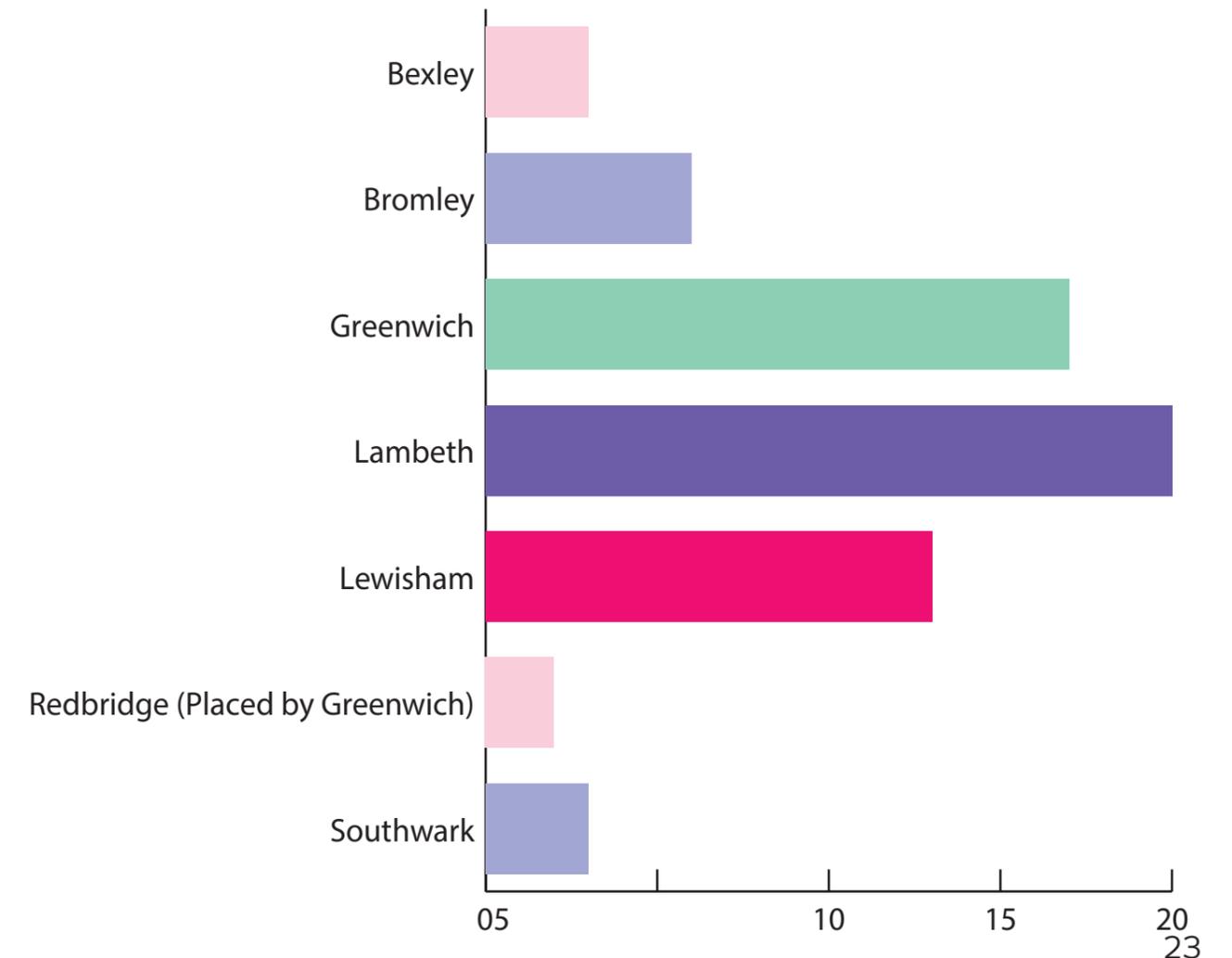
Ethnicity	Number
Black African	4
Black British	9
Black Caribbean	5
Black French	1
British Asian	2
Mixed Race	6
Not given	11
Not known	1
White British	25
Grand Total	64



Boroughs of Placements (where participants currently live)

There were seven London Boroughs represented in the research with Lambeth having the greatest number of placements (participants) (n=20), followed by Greenwich (n=17), which was closely followed by Lewisham (n=13) and Bromley (n=6). Bexley and Southwark each had 3 (n=3). Redbridge had 2 Greenwich funded residents (n=2)

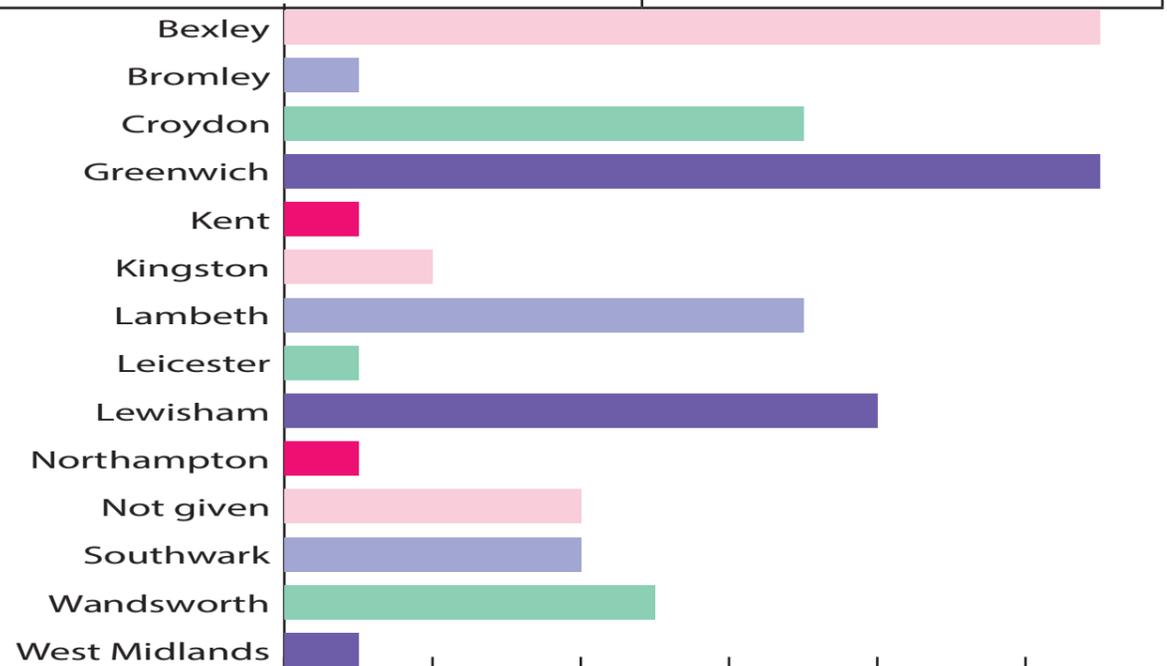
Borough of Placement	Number
Bexley	3
Bromley	6
Greenwich	17
Lambeth	20
Lewisham	13
Redbridge (Placed by Greenwich)	2
Southwark	3
Grand Total	64



Original Boroughs (Participants responsible funding authority)

There appears to be a significant number of people in settings distant from their Borough of origin. There were ten placing London Boroughs represented in the study in addition to out of area placements from the east and west Midlands. Four participants did not know what their original placing Borough was or declined to answer. The two participants from Leicester and the West Midlands asked to participate in the project.

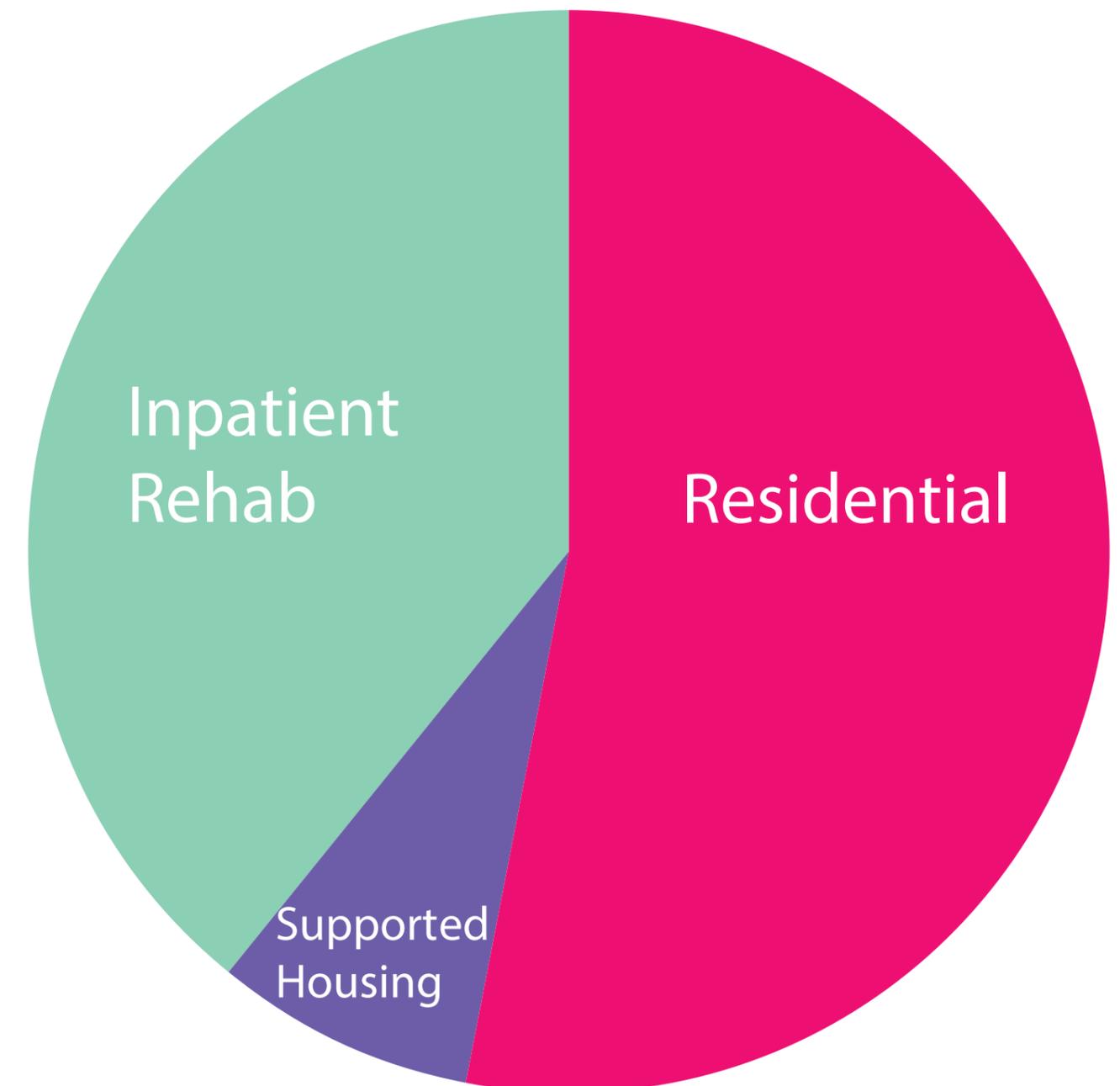
Original Borough	Number
Bexley	11
Bromley	1
Croydon	7
Greenwich	11
Kent	1
Kingston	2
Lambeth	7
Leicester	1
Lewisham	8
Northampton	1
Not given	4
Southwark	4
Wandsworth	5
West Midlands	1
Grand Total	64



Types of Unit

We visited and/or had online conversations with people from 19 different services and they fell into three different categories: Residential, Supported Housing and Inpatient Rehabilitation.

Borough of Placement	Number
Residential	34
Supported Housing	5
Inpatient Rehab	25
Grand Total	64



Conversations about Care

Listening to and engaging with participants

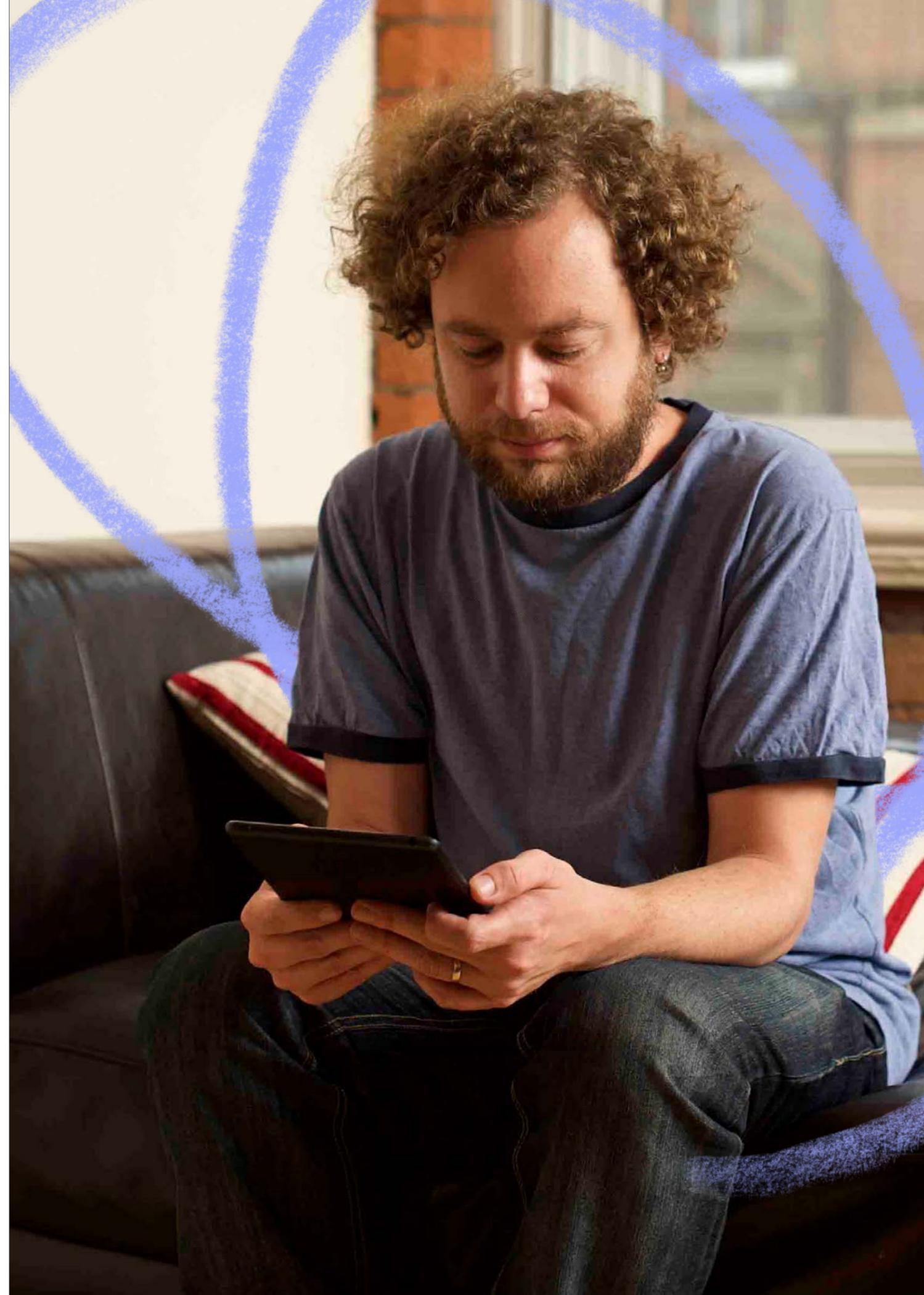
Mental illness is closely associated with many forms of inequalities. The quality of care for these disorders remains suboptimal, and there are persistent gaps in access to and receipt and experience of mental health services. Health inequalities are avoidable and unfair differences in health status and determinants between groups of people due to demographic, socioeconomic, geographical and other factors. These differences can be in relation to prevalence, access to, experience and quality of care and support, as well as opportunities and outcomes. Health inequalities can mean reduced quality of life, poorer health outcomes and early death for many people. People living with SMI experience some of the worst inequalities, with a life expectancy of up to 20 years less than the general population. Listening to, engaging with, and understanding the mental health needs and outcomes of the local population is therefore vital for good service planning and commissioning.

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

“**The communication has been much better here, much, much better. I am kept informed and I have a say in it all. We are planning for me to go there for some overnight leave before I go properly which is helping me with my anxiety**”
(Residential, Female)

Another participant also highlighted the importance that engagement can have on the individual:

“**Just because you have problems doesn't mean you don't have anything to say. It's really good to be asked to speak to you about this Personal Health (budgets) and I want to find out.... I'm chuffed you asked me. I want to know more about what I can get and how I can get it so when I meet my coordinator I can bring it up and talk about it. They need to listen to us mental health people more you know. That's how improvements are made you know....listening, knowledge, action, change...that's it, it's simple really. If they don't ask you how will they know what I want**”
(Residential, Male)



Quality of Life and Good Care

Quantifying and measuring quality of life is complex and multi-faceted and there have been many attempts to understand the elements of care that promote this sense of subjective wellbeing. Bowling and Gabriel's research (2007) identified various themes that their respondents felt gave their lives quality. These included but not limited to: social relationships; activities and leisure activities; health; psychological outlook and wellbeing; and independence. These were viewed as important for the sense of freedom they brought, for satisfaction with life; mental harmony; social attachment and having access to social contact and involvement, help; social roles; and feeling secure (2007:827). Malley and Netten (2008) state that, wherever possible service user perspectives should be used to evaluate care and they emphasise that different outcomes will be more or less important to different individuals.

The objectives of 'good care' should always be "...to improve the quality of life of people who use services and support and of their carers" (Netten 2011:ii) however quality of life is a highly subjective thing. The ethical issues involved in assessing and evaluating the care of vulnerable people is complex as is determining what acceptable and desirable care is there in the first place. It is always difficult to attribute the cause of problems or indeed successes of interventions and when asking service users to comment on the care they receive, it is possible that they have adapted to and accepted poor care as the norm and do not consider better care a possibility. This may particularly be the case with vulnerable individuals in in-patient or residential settings who feel grateful for receiving any help at all and who may be reluctant to complain or appear to be complaining. Surveys based on the 'satisfaction' of users may just reflect the gratitude of service users or their fear of losing services and Malley and Netten, (2008), draw on earlier research to argue that people are not keen to report dissatisfaction. This reluctance to criticise and to speak out may be linked to a sense of dependency and vulnerability. However, some participants did speak out about the care they received.

The majority of respondents interviewed (60%) referred to their Care as 'good or very good' eighteen percent (18%) said their Care was poor whilst twenty-two per cent were unsure.

“The care is good here no doubt about it. They care for me and I should know. I been in a few places me” (Residential, Female)

“I felt welcomed and supported since day one and the staff cannot be faulted(Residential, Female)

Support and Relationships

Most of the people who were asked about the support they currently receive and felt that it was appropriate to their needs and that staff are very generally supportive to their specific needs. The relationship between staff and residents appears for the majority of participants to be one of support, trust, honesty, and mutual respect

“Support-, it's fantastic and feel the staff genuinely love and really care for the residents. (Residential, Female)

The professional bond between many interviewees and staff was evident in the expressive way in which they referred to them:

“The staff here simply cannot be faulted. This is the right place for me and the support is 100% to the right level (Residential, Male)

This is also illustrated in the quote below from one participant who became visibly emotional when describing how much she appreciated the support she receives

“Let me tell you I feel very fortunate here, it's very good and I feel well cared for. I feel very fortunate to have such good support here. I couldn't manage without them. They are always polite and kind and nice and they've always helpful and there are lots of activities here” (Residential, Female)

Although the benefits of a close trusting relationship between health staff and recipients were extolled by the majority of participants in this research, it was not the case for all respondents. Some respondents expressed a desire for a more hands-off relationship with their health care worker rather than a friendly-supportive professional relationship. There were however, contradictions as they were generally happy with a professional and efficient approach and appreciated the distance and degree of privacy that this allowed. However, there was also evidence that the possibility of a better working relationship was often not achieved due to barriers imposed by the service user namely an unwillingness to engage. One respondent acknowledged that his lack of closeness with the health care workers was due to his “reserved personality”. He felt that his reserved nature limited the degree and depth of conversation as he did not tend to open up or divulge information or problems:

“I am reserved but I mean they stick to their side of the bargain I suppose. I don’t particularly want to move on so I’m not rude or anything but I only really speak if I have to. I just don’t tear my feelings out like some of them lot. Some days I just can’t be bothered. It’s my reserved personality (Residential, Female) ”

Participants who spoke about the level of support not being good enough spoke primarily about not having been told their rights and therefore were agitated that they were unable to access the support needed. For example, a few who were detained under the Mental Health Act, said they had not been informed of their right to advocacy and to legal advice. In essence these people spoke therefore about lack of support not just from the staff but also from the services they knew they were entitled to.

“I need an advocate, where are they? I have no control over this and I’m being stirred along by others. I need some proper advice here (Inpatient Rehab, Male) ”

Some participants had a negative experience about their care and some of the issues discussed appeared to have had existed prior to admission and had been provoked or escalated by their stay. Recurring problems included social isolation, financial difficulties and worries, challenging familial relationships and dealing with other patients were mentioned.

“I’m just used to being shipped around from place to place now. I don’t feel at home here and I don’t get on with the others. They put everything down to mental here. That lot have too much power. I’ve still got the same worries, and more money worries and family stuff and all that (Residential, Female) ”

Preparing for the move

A large number of participants (70%) identified helpful factors that had offset the impact of difficulties they had moving to their current accommodation, including preparation for the move from hospital and support from within the sector following their move. These included preparations and being fully involved in planning the move. Participants recalled efforts made by staff to prepare them for the psychological impact of being moved and help with the adjustment process

“They really listened to me and kept me up to date at every opportunity (Residential, Male) ”

Preparing for the move

Another consideration to make in relation to assessing quality of care is to look beyond the individual directly receiving care to consider everyone who is a beneficiary of care. In many cases there will be others close to the ‘service user’ who could report on the service received. Such people include friends and family who, more often than not, will be informal carers so are, in effect, co-workers in service provision. In some cases, it may be appropriate to involve them in the design of services and this may be particularly the case in relation to Personal Health Budgets. Percival et al (2013) suggest that meeting the needs of family care-givers requires sensitivity and consistency and services that are proactive and family-centred. Sufficient time, the emotional needs of patients/users and family care-givers was factored in and respondents talked the service was flexible enough to involve and respond to the family’s needs.

“I was involved with the move all the way. It really helped with my anxiety levels. Step by step and with my mum too and the community health team. I had already visited and they supported me and my mum fully...the full Monty ”
(Residential, Male)

Ongoing relationships with other service users was also highlighted as very important to some in helping them to settle in, manage their move and continuing symptoms of mental distress

“I’m really pleased with the amount of activities here, and the socialising and the games and others here are really good to talk to and definitely helped me settle in.. It served its purpose and I’m not hurting myself now because of everyone here. I never thought I’d get this far ”
(Residential, Female)

A few participants did however talk about a number of difficulties that had arisen as a result of, or had been made worse by, their stays in their current residential setting. Ironically, the provision of constant availability of support and reassurance while in their current accommodation contributed to feelings of vulnerability and fear of being eventually moved on.

“Staff are very protective here. They are always around always making sure I’m okay but I almost feel like kidnapped and I won’t be able to move on, Its worse here. ”
(Residential, Female)

Interventions

The provision of mental health and psychosocial support interventions and expressive interactive activities is an important strategy for protecting or promoting the general psychosocial wellbeing of individuals and the treatment of more serious mental health issues. Participants talked about engagement with music and art, participating in cooking sessions and the positive impact had on their mental well-being

“I’ve been able to form a music band with others here and it’s been fantastic for me” Another participant stated “I’ve trained to be a peer support worker since I’ve been here and I’m interacting with others and I’ve become more dependent.” (Residential, Male)

Avlund et al (2003) note that “social participation defines and reinforces meaningful social roles through opportunities for engagement, which in turn provides a sense of value, belonging, and attachment” (p. 95). The effect of social contact and participating in activities on wellbeing was described in many of the interviews. In contrast a few of the service users interviewed reported experiencing boredom and the sense of ‘time standing still’

“There is nothing inspiring here. The time goes so bloody slow. It’s boring Monday to Sunday” (Inpatient Rehab)

Bowser and colleagues (2018) explored the causes of boredom in men with psychotic disorders in in-patient settings and explored service users’ perception of care and found boredom to be a primary issue expressed by them. Boredom was related to a lack of meaningful engagement on hospital units, and low staff-service user interactions.

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.



“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)”

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

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

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

“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)”



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.

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

“There needs to be a lot of training on this so we can tell everyone. I’ve no idea how people access it or how much they get. We definitely need to know more”

Health care workers themselves suggested several reasons why they were unaware of the Personal Health Budget agenda, including time constraints, overburdened with heavy workloads, lacking confidence to take on new initiatives and perceived bureaucracy within the system.

There is a cognisance that service users can and should play an important role in deciding their own care and recovery, in defining optimal care, and in improving mental healthcare delivery and outcomes. Popular concepts such as patient/user-centred care, service user empowerment, and service users as partners, co-production and co-produced care, shared decision making, and informed choice illustrate the emancipation of the service user. Choice is tied to the notion of individual autonomy or freedom, a concept that has emerged largely in ethical theories of the good. For example, regarding any treatment or recovery pathway offered to service users, it is believed that giving individual choices will not just enhance their autonomy but also better inform them about their health conditions and the available treatment options (Faulkner, 2012) Arguably, there is a fundamental obligation to ensure that service users have the right to choose as well as the right to accept or to decline information. Furthermore, Beauchamp and Childress (2013) contend that, in some cases, health professionals are obliged to increase the options available to service users, whereby many autonomous actions could not occur without the health professionals and health organisation cooperating with the individual to make these options available. At the same time, the ability to exercise choice is highly valued as an expression of individual identity and autonomy. Giving service user choices has been linked to their satisfaction. It has also been suggested that service user preferences are essential to good care because the service user’s cooperation and satisfaction reflect the degree to which interventions fulfil his or her choices, values, and needs.

One individual stated on hearing about Personal Health Budgets:

“Yes, it would be a good way to express myself. I could be involved in it and it would make me feel important”

This cooperation in decision-making results in greater trust in the health professional-service user relationship. Furthermore, individuals are likely to receive greater satisfaction from the goods and services if they are directly involved in choosing them.

“No, I’ve certainly never heard of them. No definite no. The staff are nice here but they’ve never told me about these. If they did I would have remembered I would benefit from this and would like to be involved. It would be nice to be part of it”

“Yes, I would like to know more. Do I choose something for me?... yes I like that I, I would think hard about it and plan things.”

More participation of service users is seen as leading to better adherence to advice and treatment and, thus, to better health outcomes. Besides, service users’ choices are psychologically significant because the ability to have choices, express those choices, and have others respect them is central to a sense of personal worth. This is important because the service user, already with a diagnosis, may have a principal need for some sense of control in order to move forward in their lives. When service user choice is ignored or devalued or individuals are not informed of choices, service users are therefore more likely to distrust and, perhaps, disregard health recovery recommendations, which may later result in the jeopardising of the effectiveness of their treatment plan (Jonsen, Siegler, Winslade, 2015)

“No one has mentioned these to me. Perhaps they don’t know but then I could miss out couldn’t I”

Individuals will not be able to engage with the Personal Health agenda if they do not have the necessary information. Choice does not depend only on having information, as it also relies on the skill of understanding the information given (Rice T. 2001). The lack of knowledge about in this case Personal Health Budgets exposes service users to additional stress.

“I’m worried I’m missing out here”.

The assumptions behind Personal Health Budgets firstly, on the existence that service users and health professional understand the concept and that service users are able and prepared to actively participate in choosing the service they want to receive. “Choice is also supposed to give service users control over their care... it is recognised that many service users still want and need help in identifying the outcomes they want to achieve (Orellana, 2010). Much therefore depends on the skill levels of those carrying out the assessment. When we explained the concept one participant stated

Barriers: Lack of Knowledge

“I need to write everything down as my memory is not great. I sometimes get confused so I’d need someone to help me and to have some patience with me. (Residential, Male) ”

People with mental health issues may face barriers in accessing services and support. It is clear that respondents are not aware of Personal Health Budgets and what is available to them. The availability of good support planning and brokerage support services will be particularly important in mental health if parity of access to Personal Health Budgets is to be a reality (Jones et al 2018).

Insights into Possible Challenges

The research provides valuable insights into the possible challenges of implementing Personal Health Budgets. There were a number of areas in which interviewees expressed concerns including worries and delays over the administrative process and the burden of managing the budget. For a number of reasons, the process of the application itself was seen by many as a major barrier.

“Where does it come from? Are there loads of forms like benefits. It stresses me out (Inpatient Rehab, Male) ”

After the concept was explained by the research team, understandably there continued to be levels uncertainty about what Personal Health Budgets could and could not be used for. Many remained confused about the concept but were keen to know more. Participants were interested to know more about the potential size of the budget, how long the budget would last for and whether the budget could be used for wider well-being gains.

“I like the idea but tell me more...like how long does it last, how do I get it and how much do I have to spend and do I have to go to one of those reviews all the time? (Residential, Male) ”

Even after explanation, some (n=5) did not understand that the budget was a ‘personalised’ funding allocation and thought they had to compete with other residents which would make them reluctant to apply. Some interviewees (n=11) stated that the process of applying would cause considerable anxiety and having a budget potentially turned down could cause huge disappointment and frustration would potentially impact on individuals making a request for a budget.

“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”

Swimming

Two individuals (3.1%) would attend swimming groups with both having used this previously as a therapeutic activity.

“it would be therapeutic for me. It relaxes my body and mind and keeps me fit. I also like attending swimming groups and I feel more social. It would keep me out of hospital by keeping my mind on other things and keep me occupied”

We’ve long known that swimming is an excellent cardiovascular exercise that strengthens the heart and circulatory system. But it also really benefits mental health. It helps the brain to release mood-boosting brain chemicals, repair damage to brain cells and grow brain cells. Swimming can help lower anxiety and depression. Recent research has shown that swimming can have an anti-depressant effect, reducing depressive symptoms with a positive impact on those struggling with depression. In addition, swimming with a group, has additional mental health benefits. Swimming with a group is typically a social affair.

Alternative and Relaxation Therapies

Service users (4.3%) thought that having a Personal Health Budget to access a sauna or alternative therapies could improve their autonomy, motivation and quality of life. Participants valued the ability to choose their own treatment and to have flexibility to specify their own needs and identify appropriate services.

“I’d love to visit a Sauna one week and maybe something different some other therapy or oils the week after. It would be great to have the choice too and then I’d feel in control more. They make you feel calm and the ointments in it are therapeutic and definitely help me feel fore motivated to continue”

Personal Assistants

Four participants (6.25%) spoke about specifically employing their own personal assistants in order to access services and in particular employment. This might be for physical reasons or due to anxiety, but the key issue is the regular need for support with community integration and interaction:

“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”

Therapeutic interests

Fishing

One individual stated he would use a Personal Health Budget to purchase fishing equipment and would go fishing regularly. His reasons included being able to reminisce about what had been a very happy childhood. Fishing requires concentration and focus. This concentration and focus takes our mind off of the everyday stresses and internal conflicts that confront all of us. Studies have shown that being in nature and engaging in recreational activities like fishing, reduces psychological stress.

“I used to love night fishing. It's quiet and gets you away from the hustle and bustle. It's just you and the rod it's just peaceful and its definitely good for my mental health”

Music

Two participants (3.1%) informed us that they would spend a personal health budget on music related activities. One participant informed us that they would like regular time in a music studio whilst the other person stated she would like to purchase an electric drum kit. We have all experienced the feeling of euphoria that music gives us. In the right setting and in the right context, music can create a powerful feeling of well-being. In fact, listening to and playing music is one of the few activities that has been scientifically proven, time and time again, to lift our mood. Anxiety and stress are the opposite of relaxing and creating music or playing an instrument are great for relaxing. Stress and anxiety are very detrimental to a person's mental health so anything that helps reduce stress and anxiety is invariably beneficial to mental health

“I have been dreaming of playing the drums. It helps me to be creative and it frees my mind”

“It is something I can do when I am on my own. it will also help socially as I would meet new people”

Exploring

One participant spoke of having previously had a telescope and shortwave radio and enjoys exploring which helps with his concentration, keeps him focused and improves his overall mood. He no longer has the equipment needed and would use a Personal Health Budget to purchase a telescope

“I know about these things and would like to explore more. I think being occupied is a good thing for my health. The voices don't bother me when I'm occupied”

Limitations of a Personal Health Budget

Support with Immigration

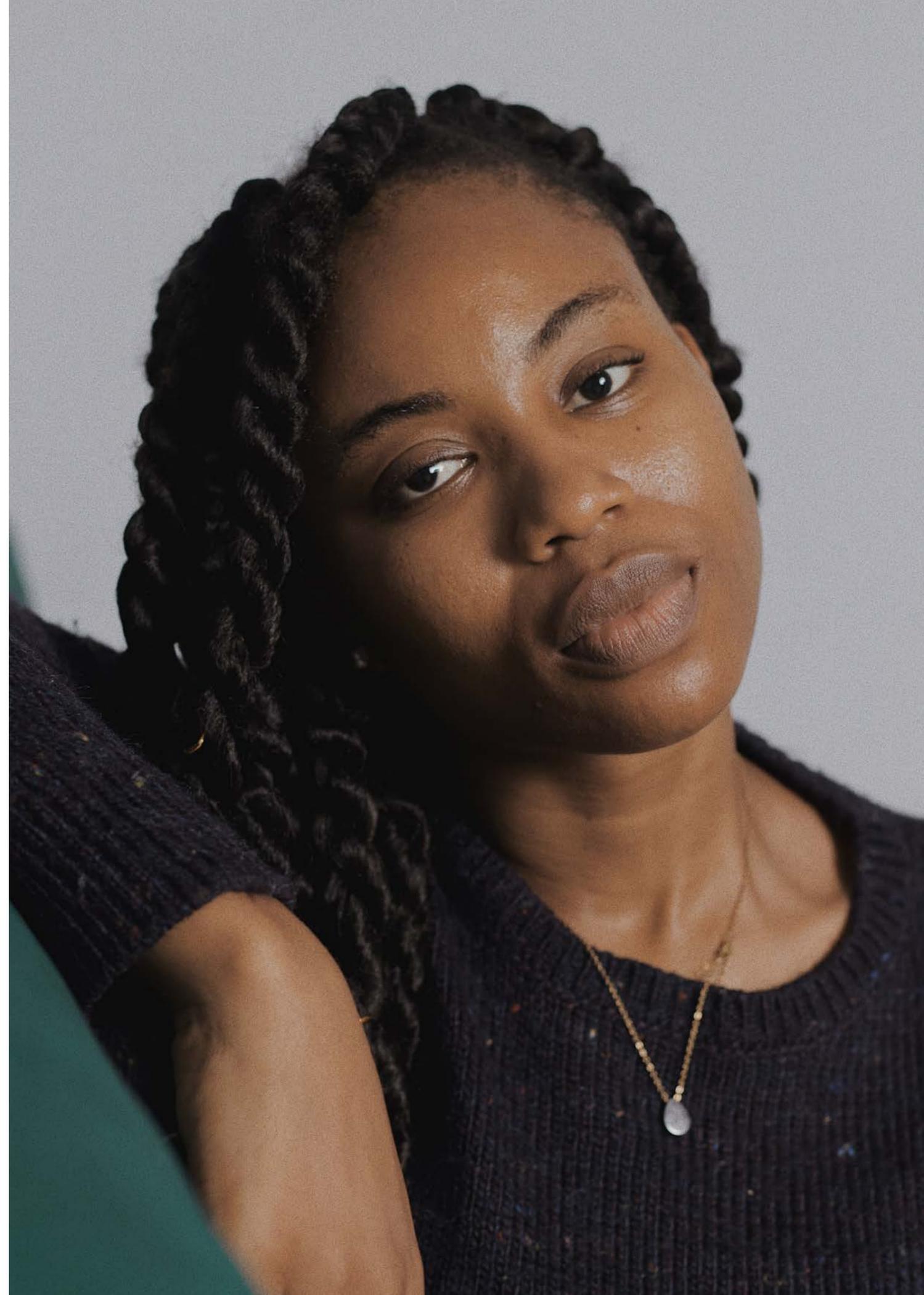
One participant spoke of needing to stay in the UK for the sake of his mental health. He did not say specifically what could be paid for via Personal Health Budget in order to achieve this goal but stated he would like to use a Personal Health Budget to help with his immigration status if possible:

👉 **If I cannot stay in UK, my life is over. It's hard to say about why so if I had a budget it would help me** 👈

Whilst it may not be possible for support with immigration to be funded by a Personal Health Budget at the current time, it needs to be acknowledged that the stresses and challenges at different stages of the migration process including the immigration process itself can lead to psychological distress and physical ailments. Bhugra and Cochrane (2001) in 'Psychiatry in Multicultural Britain Acculturation' have observed that deculturation as a process of settling down in a new and alien culture will also produce psychological distress and can 'lead to the development of mental illnesses such as adjustment reactions, eating disorders, affective illness, paranoid reactions and common mental disorders'. In addition, issues such as lack of familiarity about services, low income, racism, and isolation, housing and challenges with the immigration system can add to psychological stresses. Studies suggest that exile related stressors maybe as powerful as events prior to flight and therefore impact hugely on health.

Helping a person achieve better mental health and move towards recovery needs to address all relevant issues as far as possible. Requests which are excluded from provision such as support with immigration status need to be documented and the impact analysed.

This research provides a snapshot of the opportunities in rolling out Personal Health Budgets. The narratives suggest that Personal Health Budgets when explained are associated by participants with improvements in quality of life and psychological wellbeing and greater independence. We also know from our ongoing engagement with people with mental health problems, that having greater choice and control has therapeutic benefits in itself, particularly for people who have become disempowered after many years in services, and can improve people's confidence and self-esteem. Generally service users thought that having a Personal Health Budget would improve their autonomy, motivation, choice, control, independence and quality of life.



Recommendations

Effective Communication and continuity of care

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.

In order to ensure that the experience of service users is a positive one, clients must feel that they are important, listened too and fully informed about their choices. Health professionals must also ensure that communication is clear, accurate, effective and professional. The importance of effective communication moves beyond meeting basic needs, workers should develop relationship founded on trust, compassion, knowledge, experience, cultural awareness and empathy, all of which are essential to ensuring that the experience of care is a positive one.

Providers must ensure that staff are aware of the need to communicate essential information to clients and their families as quickly as possible. Structures and processes need to be monitored, improved and continually reviewed in order to share such information. Adding Personal Health Budgets to PROM could be considered.

Mental health staff on inpatient wards need clear understanding of Personal Health Budgets as these can be used for step down to enable individuals to become more independent. This includes assistance to learn to cook, help to book appointments and attend these. Asking questions such as “what would help you to be more independent?” will enable clients to be given choice and control of what is provided through a Personal Health Budget.

Providers must ensure that workers undertake regular training and monitoring in communication skills ensuring that all interactions maintain dignity, respect and the necessary safety requirements. An important element of the communication between staff and client/client’s family is ensuring that workers effectively explain unfamiliar terminology and processes so that all parties are fully informed about the implications and arrangements for their care.

Providers must also ensure that care-workers undertake training to ensure that the service they provide and the interactions that they have with clients is culturally appropriate and sensitive to their individual requirements.

Training and Education

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 thus making Personal Health Budget take up more culturally competent.

Empower communities to act as a forum in which individuals and organisations can exchange information, share experiences and work on specific Personal Health Budget’s with members of their community to maximise recovery.

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. Training needs to be provided for all relevant parties working with clients/service users to ensure that they are able to face the challenge of fully understanding and adapting to Personal Health Budgets. Comprehensive and myth busting training needs to be pro-active in educating health staff so they have a full and accurate understanding of Personal Health Budgets and the actual level of Personal Health Budget support to which clients are entitled. It is also necessary to have consistent and on-going professional development training for mental health service providers to increase knowledge and explore different approaches to encourage engagement with the Personal Health Budget agenda.

Agencies need to address the lack of understanding of Personal Health Budget’s in the wider mental health system. Relationships need to be developed between voluntary, faith and community organisations and mainstream agencies, developing and sharing good practice standards for wide implementation.

Community organisations and individuals with Lived Experience should be employed and involved in the delivery of education and training programmes to communities and service users in order to improve take up.

Services need to work in partnership with community groups and voluntary organisations to ensure that the services provided are responsive to client groups.

Training and Education

Innovative approaches need to be employed to empower communities whereby they can act as a forum in which individuals and organisations can exchange information, share experiences and work on specific Personal Health Budget's with members of their community. These events can also highlight issues and gaps in service provision for which lobbying is needed. Service providers need to ensure equal opportunities for BAME individuals thus making Personal Health Budget take up more culturally competent.

In order to combat service user anxiety there needs to be a multi-level community education and training process where possible members of the community provide positive role models and demonstrate the possibility of positive outcomes and counter the possible negative beliefs associated with a Personal Health Budget. Strategies need to be multi-faceted and have a co-ordinated approach to ensure that they reach community members, individuals and institutions.

Personal Health Budgets offer an opportunity to move towards genuine shared decision-making in which both the lived expertise of the person/carer and the clinical skills of the professional are recognised, with decision-making powers shared more equally in an environment of mutual respect allowing providers to be innovative and creative. Judgments about levels of risk (to patient safety, professional reputation or organisational finance or safety of others) will significantly influence the way in which Personal Health Budget programmes are implemented in practice. Positive risk taking with mitigation and contingency is needed and risk assessments will need to be completed. On occasions items such as pet insurance may need to be part of the Personal Health Budget. It is crucial that adequate support is provided to staff involved in all aspects of the process.

Advocacy and Befriending and Links with Community Networks and Social Prescribers

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.

Advocacy was identified in the research as a comprehensive and successful way in which to potentially engage service users and to eventually result in effective participation in the processes of planning and implementing Personal Health Budgets. An advocate, who both listens and when appropriate speaks for a user, works to enable users to express themselves, access and explore relevant information and service options and be empowered to promote and secure their entitlements.

There are many different types of advocacy and it may be appropriate to adopt only one or a mixture of approaches at different times and in different circumstances. The main types of advocacy are – self, group, peer, formal, professional or paid, and or legal. Health professionals will need to work with individuals and agencies to service users feel confident in accessing and utilising Personal Health Budgets.

Befriending is a strategy which involves helping users and/or potential users to make choices about their lives, and to particularly support them during important transition points to enable them to support them on their recovery. Commissioners may also want to consider linking into or funding time specific goal orientated mentoring, which is more structured and time limited in order to work with individuals to utilise a Personal Health Budget.

Funding and linking in to community advocate and befriending and mentoring programmes (in all the many different forms as appropriate) in order to improve access and equitable take up of Personal Health Budgets. Formal, professional or paid advocates would need to be trained in Personal Health Budgets so that they are then able to offer education and training and work with volunteers and mentors from communities in order to ensure users are better informed.

Systems

Establish clear pathways and systems to implement Personal Health Budgets which are equitable, clear, fast and where delays in decisions and payments are avoided. Ensure the pathways and systems are continually monitored, reviewed and improved systems.

Establish clear and quick decision-making processes to look at eligibility for a Personal Health Budget, what the budget can cover, who can make the funding decision and who pays.

It is essential to establish systems to implement Personal Health Budgets that are decided equitably, clear, jargon free and as fast as possible, therefore mitigating against service user anxiety, fear and demoralisation. Administrative systems need to be set up from the onset to avoid delays and potential failures in payments thus potentially disrupting vital care and support provisions.

Commissioners identified these challenges and that clear and quick decision making is crucial in the successful implementation of Personal Health Budgets.

The importance of service user involvement in a successful rollout and take up of Personal Health Budgets and developing systems is crucial and will shift a mental health service ideology from a hierarchical culture to a participative, inclusive and solution focused approach that seeks to empower users and work in partnership with providers order to improve mental health services.

Accessibility and engagement with Personal Health Budgets

Jointly identify and address potential barriers to accessing and uptake of Personal Health Budgets.

In reality there are many potential barriers to accessing Personal Health Budgets. The most significant of which are noted from our research to include knowledge and understanding the concept, the concerns about associations with the Welfare System, the actual name itself, language, cultural factors, institutional factors to include how services and systems are organised, a lack of information about Personal Health Budgets in the health system, and pressure from limited resources and systems. It is therefore important that health professionals, lived experience practitioners and agencies collaborate on issues and solutions to the problems of access and take up to ensure that those in need of help and support receive the Personal Health Budget they require.

Cultural sensitivity and understanding – perception, stigma, language, education and training

Understand how cultural interpretations may impact and ensure a culturally sensitive approach so users have equal access to Personal Health Budgets.

Recognising the importance of culture and recognizing that culture is not static and understanding how the dominant culture within a society shapes and influences all aspects of institutional service provision and development is essential to any discourse on the challenges facing both service users and the systems and institutions comprising health care provision. Issues of accessibility for certain groups can be underpinned by culturally specific understandings of mental health, stigmatisation of mental health issues and the role of treating illnesses. Many societies and cultures stigmatise mental health and the diagnosis of mental illness may be unreliable cross culturally.

Unless cultural interpretations are taken into consideration, communities will not access services. A culturally sensitive approach is therefore necessary if users are to receive appropriate care and access to Personal Health Budgets. Understanding how these cultural interpretations may impact on potential access is essential if service providers want to ensure those needing help are getting the help they need via a Personal Health Budget.

Language Support

Ensure access to appropriate interpreters and provision of culturally sensitive Personal Health Budget information in a range of languages.

It is essential that service users have access to a choice of interpreter, one perhaps not from their own culture, if they do don't feel comfortable or secure with an interpreter they are unlikely to be open about their situation.

Service providers must ensure the availability of a range of literature/information that is jargon free, in relevant languages and culturally sensitive. Health providers should have targeted written/video information in community languages produced in partnership with people with lived experience, voluntary and community organisations on Personal Health Budget service provision and a step by step guide on accessing a Personal Health Budget.

User involvement

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.

Ensure the ongoing involvement of users to improve how Personal Health Budgets are implemented and address any issues. Look at creative and innovative ways to gain client feedback and participation in service design and delivery. Interestingly, the service users interviewed evidently appreciated the opportunity to contribute to the research; however, some then placed very little value in user participation in general. It is important to note that their priorities lay very much with sustaining their mental and physical health and their Recovery journey and consequently service user involvement in this context took second place. In essence some have become disengaged and disempowered and therefore the formal structure of consultations, forums and user-led meetings may be so far removed from their everyday reality. Commissioners should therefore consider the role of advocacy as a mechanism to improve user involvement.

It is important to reiterate that this research is based on a small scale and although valuable in itself and to some extent able to be generalized in terms of the wider community. Individuals will inevitably occupy different positions and have had different experiences which may be less likely to mitigate against participation. Consequently, it should not be concluded that user participation is unimportant or irrelevant, rather that these findings emphasise the importance of holistic working in order to combat the practical barriers which may prevent users from feeling able to make a valuable and necessary contribution to their own and their communities mental health care provision. It remains an important strategy to whenever possible encourage and support service users to contribute to service planning, development and delivery in whatever way they feel possible. Such an approach will inevitably require innovative and creative thinking in terms of engaging with users to ensure that it is itself user led in terms of appropriate strategies informed by cultural understandings and practical considerations.

It would be helpful to explore opportunities to canvas views and feedback (obviously with informed consent) to encourage and promote user-led informal groups which provide alternative mechanisms for individuals to discuss their experiences in an informal setting, examples of such groups could be sewing, art, music, poetry, creative writing and cooking.

Encourage and obtain feedback from partner agencies via third party reporting. This may mean that if a client is referred by a partner agency their views and opinions in Personal Health Budgets may be obtained by the referred to agency via their own innovative method and reported back to the original agency.

Evaluation, consultation and planning / funding future services

See recommendation under User involvement above - 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.

Analyse how clients use Personal Health Budgets and evaluate how far the outcomes achieved with analysis of client feedback and measures on the difference the budgets have made. Keep a record of requests which have been turned down and analyse the reason for the refusal.

Fund a formal evaluation of the progress of Personal Health Budget implementation in July 2023.

Have an action plan in place to incorporate the report recommendations showing time scales and those responsible for each action.

The need for, and positive impact of, effective and relevant evaluation and consultation processes is essential. It is therefore important that all service providers regularly review their evaluation and consultation procedures in order to make services more user-friendly, culturally competent, more accessible and more effective and therefore successful in terms of the long-term health of those with mental health issues. If carried out in consultation with stakeholders and users, services can tailor their provision in order to effectively meet the specific needs of their client group.

Evaluation, consultation and planning / funding future services

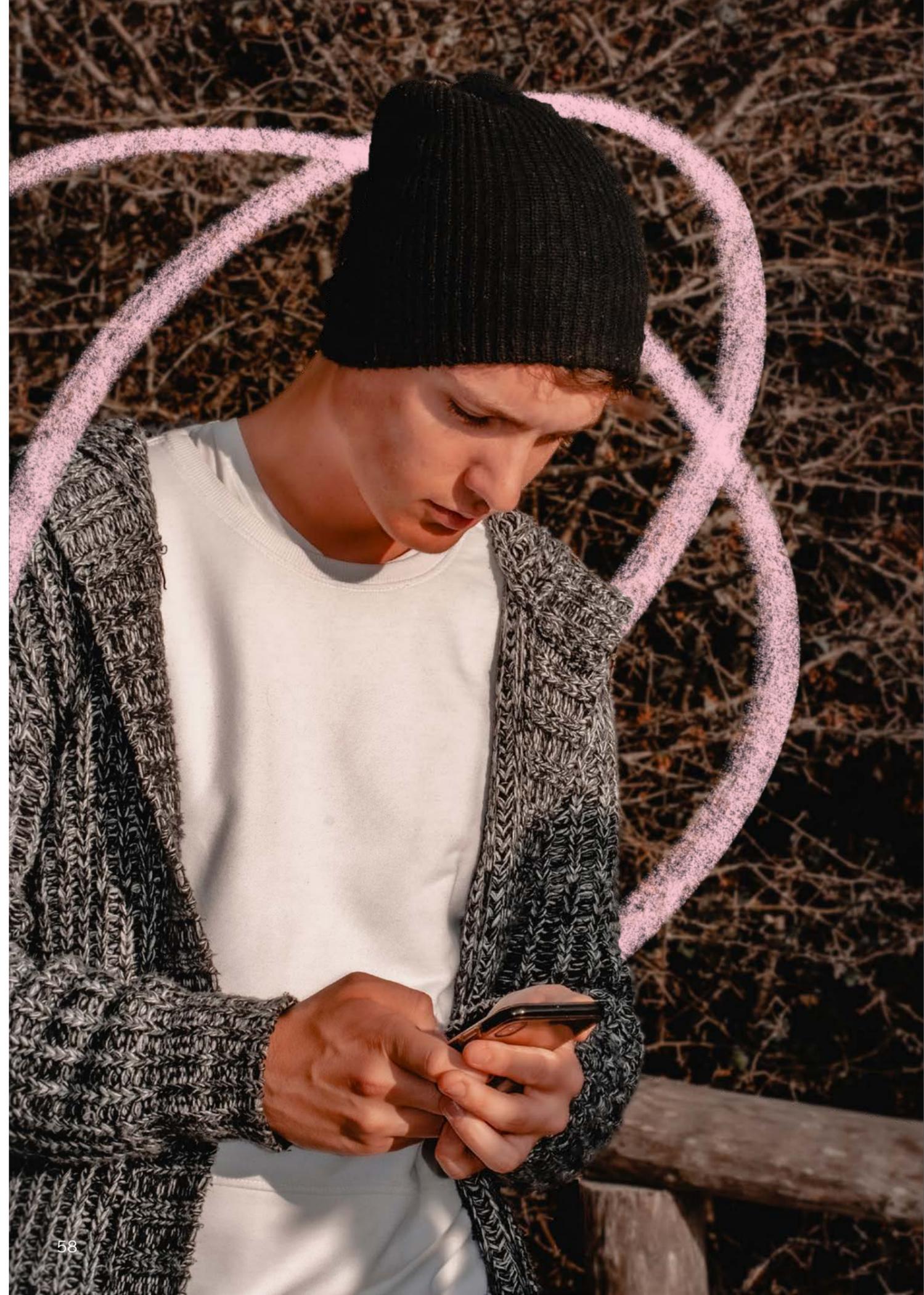
Evaluation, consultation and planning mechanisms should be in place to incorporate user feedback into Personal Health Budget services. These mechanisms need to allow for innovative ways of engaging with users that may be less formal than traditional forms of consultation; engagement is therefore on the users' terms rather than through a pre-set format and consequently more likely to encourage participation (see recommendations for user involvement for possible suggestions).

The evaluation process for service providers needs to be regular and thorough, with specific consideration of the service user. A good evaluation process should include the following: - feedback from service users, community groups, carers and families - confirm that the Personal Health Budget is effective and meets the needs and wishes of the service user - review payment provision, collect and maintain accurate and detailed outcomes- incorporate recommendations for service improvement based on the information obtained.

Working with individuals with mental health care needs and implementing Personal Health Budgets is both complex and intensive. A wide range of Personal Health Budget programmes have been implemented in a variety of settings across the country. However, in many cases they face significant challenges along the way, and they often require substantial changes to be made to and across existing systems. Staff should therefore receive regular supervision, positive and constructive feedback, and adequate non-contact time. This should also include support for family members and friends, such as drop-in sessions, access to information and advice and a space for both users and their families to give and receive feedback.

The outcomes of Personal Health Budgets will be dependent to a large extent on the way in which they are implemented, and the people and team involved in implementing them. There will need to be close links with local systems in each area. Whilst there will be variations in the process in different boroughs, an overarching aim is for as much standardisation as possible.

The overall impact of Personal Health Budgets will be difficult to predict where there is also potential significant local variation in implementation.



Appendix A

Guide used when engaging with service users:

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

Generic Information

How would you like to be addressed?

Age, Ethnicity, Borough of residence

Can you tell us about yourself and your mental health?

About where you live - Tell us about where you are living/staying at the moment.

- Rehab ward, Supported accommodation, etc
- Do you feel 'at home' here? If not, what would make the difference and what support do you feel you would need?
- Do you feel able to build on the skills you already have

Do you feel this is the right place for you with the right amount of support?

- Do you know how long you may be living/staying here?

How were you involved in moving here?

- were you given choices?
- Were your preferences considered
- Who was involved in the planning and support package?
- How could you have been better involved in the planning & decision? e.g. given more information, visited, improved communication from staff

If you have recently moved, what was the move like?

- Were you supported?
- What helped it go smoothly or what would have helped?

If you feel ready to move on, tell me about the plans

- Are you involved in planning and do you feel in control of the process? Do you feel listened to?
- Are you kept up to date?
- Are staff working alongside you to help you prepare? Is this helpful?
- What else would help?

About your day to day life

Tell us about your day to day life & what is important to you?

- e.g. education/training, relationships, health, social life, work life, hobbies, spiritual life

What is going well? What are you pleased with?

Are there things you are keen to improve?

- What would be the main thing you would like to improve?
- What would help you with this

Personal Health Budgets

Has anyone explained or what do you understand about Personal Health Budgets? – Explain concept here

Think about the things that you have identified that might help you to be as happy and healthy as possible. Is there one thing that (if you had a bit of money) you would buy or do, or do differently?

Tell me about that and do you think it would make you feel better about yourself in respect of your quality of life and well-being.

How would you know that it had made a difference?

Would help you feel safe and secure?

Do you think it would increase your mobility and physical activity?

Would it enable you to be more involved in family and/or the community?

Further involvement

Can we contact you again?

Is there anything else that you would want to tell us?

Outcomes we expect to receive as part of these conversations:

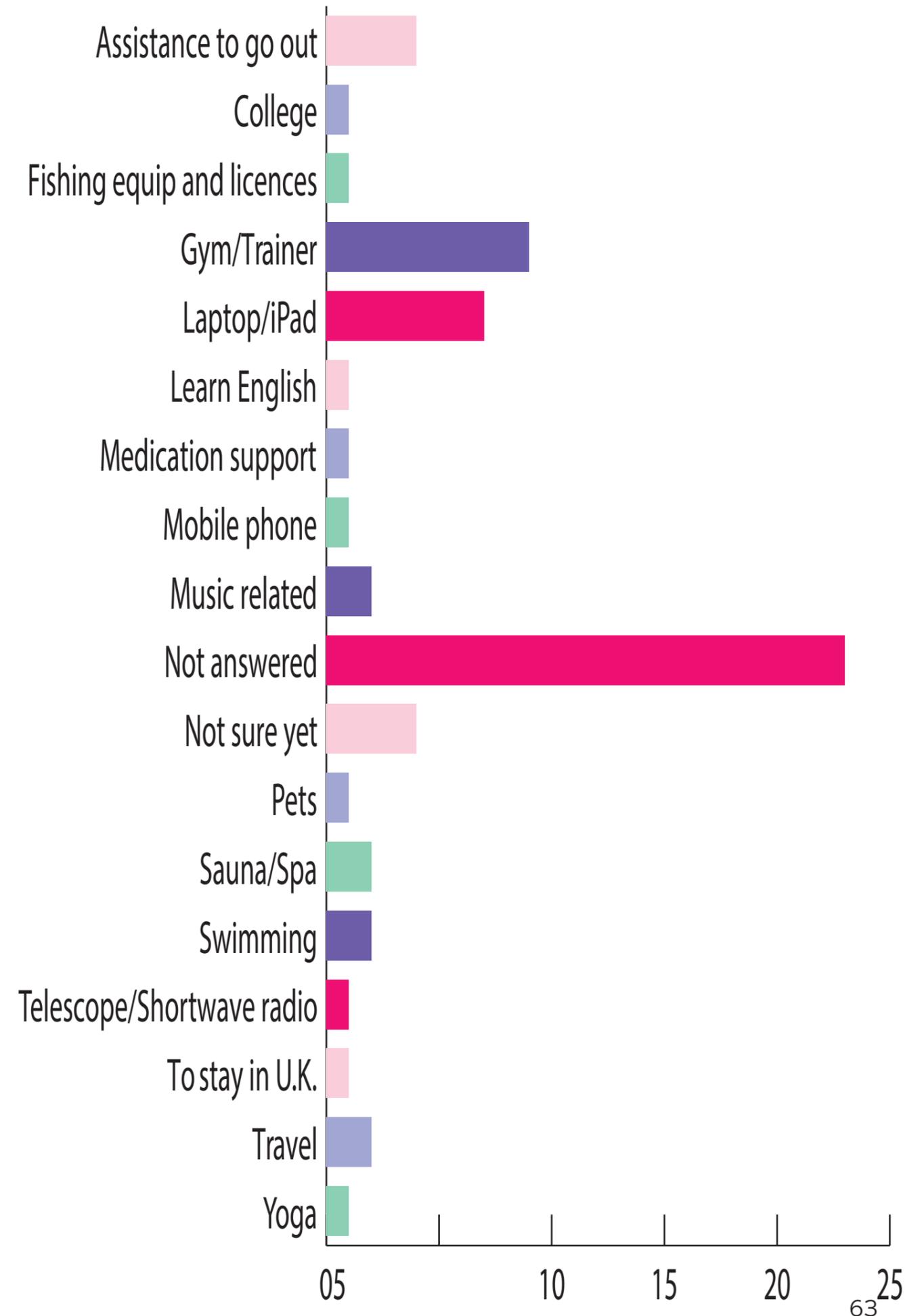
- How much choice and control people currently feel they have in decision making in their home environment and any move
- How we can support more choice and control – in staff group and with providers
- The sorts of areas people would use Personal Health Budgets and their impact
- How we would measure such an approach.

For information please email David Palmer: dpalmer@mindinbexley.org.uk

Appendix B

How many participants would like a Personal Health Budget and what would they use it for?

Personal Health Budget would be spent on...	Number
Assistance to go out	4
College	1
Fishing equip and licences	1
Gym/Trainer	9
Laptop/iPad	7
Learn English	1
Medication support	1
Mobile phone	1
Music related	2
Not answered	23
Not sure yet	4
Pets	1
Sauna/Spa	2
Swimming	2
Telescope/Shortwave radio	1
To stay in U.K.	1
Travel	2
Yoga	1
Grand Total	64



References

Alakeson, V. (2007a). The contribution of self-direction to improving the quality of mental health services, US Department of Health and Human Services.

Alakeson, V. (2007b). Putting patients in control: the case for extending self-direction into the NHS. London, Social Market Foundation.

Brewis, R. and Fitzgerald, J. (2010) Citizenship in Health: Self-direction theory to practice. Wythall, West Midlands: In Control Partnerships.

Bowling, A and Gabriel, Z (2007) Lay theories of quality of life in older age. *Ageing & Society* 27, 827–848

Cabinet Office (2007). HM Government Policy Review. Building on Progress: Public Services. London, Cabinet Office.

Coyle, D. (2011). “Impact of person-centred thinking and personal budgets in mental health services: reporting a UK pilot.” *Journal of Psychiatric and Mental Health Nursing* 18(9): 796-803

Curry, N. and Ham, C. (2010). Clinical and service integration. the route to improved outcomes London, The King’s Fund

Department of Health (2009) Personal Health Budgets: First Steps, Department of Health, London.

Department of Health (2010) Equity and Excellence – Liberating the NHS, Department of Health, London.

Department of Health (2016). The Government’s mandate to NHS England for 2016-17. London: Department of Health.

Denzin, N. K., and Lincoln, Y. S. (Eds.). (1994). Handbook of qualitative research. Thousand Oaks, CA: Sage.

Duffy, S. (2010) Personalisation in Mental Health. Sheffield: Centre for Welfare Reform in association with Yorkshire and Humberside Improvement Partnership, Care Pathways and Packages Project & Association of Directors of Adult Social Services.

Faulkner, A (2012). The Right to Take Risks: Service Users’ Views of Risk in Adult Social Care. Joseph Rowntree Foundation: York

Jacobsen, K and Landau, L ‘(2003) The Dual Imperative in Refugee Research: Some Methodological and Ethical Considerations in Social Science Research on Forced Migration’, *Disasters*, Vol. 27 (3): 185-206,

Jeffri, J. (2004). Research on the individual artist: seeking the solitary singer. *Journal of Arts Management, Law and Society*, 34 (1) 9-23

Jones, K., Caiels, J., Forder, J., Windle, K., Welch, E., Dolan, P., Glendinning, C. and King, D. (2010). Early experiences of implementing personal health budgets. PSSRU discussion paper no. 2726/2. Personal Social Services Research Unit, University of Kent.

Jones, K., Forder, J., Welch, E., Caiels, J. and Fox, D. (2017). Personal Health Budgets: Process and context following the national pilot programme. Personal Social Services Research Unit, the University of Kent. Canterbury.

Jones, K, Welch, E, Caiels, j, Windle, K, Forder, J, Davidson, J, Dolan, P, Glendinning, C, Irvine, A and King, D (2020) Experiences of implementing personal health budgets: 2 interim report.

PSSRU discussion paper no. 2747/2. Personal Social Services Research Unit, University of Kent.

NHS. The NHS long term plan. 2019. <https://www.longtermplan.nhs.uk/>

Perkins, R. & Slade, M. (2012) Recovery in England: Transforming statutory services? *International Review of Psychiatry*, 24(1): 29–39

Ritchie, J. and Spencer, L. (1994). Qualitative data analysis for applied policy research” by Jane Ritchie and Liz Spencer in A. Bryman and R. G. Burgess [eds.] “Analyzing qualitative data”, 1994, pp.173-194
<https://www.england.nhs.uk/publication/guidance-on-the-legal-rights-to-have-personal-health-budgets-and-personal-wheelchair-budgets/>

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The views expressed in this report are those of the authors and are not necessarily those of the South London Mental Health & Community Partnership (SLP) and South East London CCG



Join the fight for better mental health!

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