Expanding the Horizons of the s117 Personal Health Budget for Mental Health

A review of the use of Personal Health Budgets by people from black and minority ethnic communities

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Author: Esther Omotola Ayoola

Race Equality Foundation

nsun National Survivor User Network

Contents

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Jabeer Butt	***Race Equality Foundation***
Esther Omotola Ayoola	***Race Equality Foundation***
Akiko Hart	***NSUN***
Sarah Yiannoullou	***NSUN***
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Executive Summary

Background

Over the past two decades, considerable efforts have been made to draw principles of personalisation, a concept strategically implemented within adult social care, to the forefront of modern healthcare in the UK. By adopting a plan for universal personalised care, the NHS seeks to ensure that this style of care becomes 'business as usual' for 2.5 million people by 2024, and 5 million people by 2028/29 (NHS England, 2019a). A key outcome of this transformation has included a national rollout of the personal health budget (PHB) initiative, which, as of December 2019, has been further refined in order to meet the needs of people who are Section 117 eligible.

The evolution of personalisation means that people with chronic health conditions now have access to an enhanced, needs-based system of care that is designed to supersede the longstanding 'one-size-fits-all' approaches. The introduction of the PHB has further enriched the personalised care offer by utilising a nationwide, small budget model that provides the individual with an increased level of control over their health management. Recent literature has reviewed a range of personalisation and personalised care initiatives across the UK, with evidence demonstrating that this new integrated style of care is more effective than established approaches that are predominantly clinically managed (Forder et al, 2012). Thus far, the implications of this new system of healthcare have been identified as being largely beneficial to people with enduring mental health needs in general (Coyle, 2016). However, ongoing evaluations of personalisation in mental healthcare have still not been extended to notable subpopulations within society such as racial and ethnic minority groups, in spite of the indisputable knowledge concerning underlying health inequalities in mental healthcare provision for people within these groups. For people from black and minority ethnic backgrounds specifically, in order for PHBs to be identified as successful, they must minimise barriers to accessing mental health provision. Hence, the primary objective must be for healthcare commissioners to provide robust systems of support for enhancing mental wellbeing, that also incorporate the multiple facets of a person's ethnic and cultural background as standard. In turn, this will serve to reduce the health inequalities that reproduce the

racial disparities that are consistently observed in mental health care and outcomes for individuals from black and minority ethnic groups.

The following report is focused on reviewing the newly legislated NHS Personal Health Budgets (PHBs) for individuals who have met the eligibility criteria under Section 117 of the Mental Health Act, and; who identify as being from a black and minority ethnic background, and; who are receiving continuing care support under the remit of one of two Clinical Commissioning Groups (CCGs) in some of the UK's most populated urban areas, Birmingham and Solihull CCG and City and Hackney NHS CCG.

Findings

We researched and reviewed literature on the experiences of personalised care and the personalisation of mental health support among black and minority ethnic communities. We observed that the vast majority of evidence focused on 'personal budgets', which are managed by Local Authority adult social care teams, due to the novelty of personal health budgets there was a limited amount of literature concerning them. We also looked specifically at the origins and evolution of the PHB and the implications of its development on mental health and wellbeing. Overall, studies highlighted a need for empowering people from black and minority ethnic communities to broker the support that they require to meet their needs, particularly with regards to their culture and mental health. Though useful in theory, little discussion on the limited availability of such support and lack of adequate practitioner signposting has ensued, thus reinstating the need for VCSE organisations to work in partnership with CCGs in order to address this deficit.

Following a thematic analysis of interview transcripts, data were coded into 3 main themes that were comprised of 10 subthemes:

1) Successfully Navigating the PHB System

a) Knowledge and understanding of PHBs

b) Impact of Carer/Key Worker Support

c) Scope of the budget

d) Managing and editing the budget

2) **Personalisation**

a) Personal Responsibilities and the Role of the Family

b) General satisfaction with PHBs

3) My Culture and My Mental Health: Expanding the Horizons of the s117 PHB

a) Race, Ethnicity and Heritage

b) Nutrition and Lifestyle

c) Religion and Belief

d) Music and photography

Recommendations

- In the future, it is recommended that CCGs work to build upon the information that is currently offered to people from black and minority ethnic groups who are in receipt of a s117 PHB, as clear, consistent, accessible information regarding budget management and personalisation appears to be critical yet lacking. This has implications for personal empowerment which literature has demonstrated to be of increased significance for many people from black and minority ethnic communities.
- PHBs can be improved by expanding the scope of the PHB provision to ensure that it includes a wider range of culturally-considerate partner support options (including support with accessing ethnic cuisine, specialist support worker/therapist options), as well as space to reflect upon the impact of mental health difficulties on the self and the family as this is fundamental to wellbeing.
- To make PHBs and engagement with professionals more appealing and useful to budget-holders, a diverse, knowledgeable and relatable staff workforce that can effectively and consistently demonstrate an understanding of the intersections of race, culture and mental health is crucial. Failing this, reductions in engagement by people from black and minority ethnic communities with mental health services are likely to persist.
- PHBs could also be improved by adopting a modern, culturally-personalised approach at a CCG-wide and Trust-wide level, it will be possible to share best practice moving forward with multidisciplinary staff teams in order to ensure

that they possess adequate knowledge and skills to effectively engage with and better implement PHBs for black and minority ethnic people in receipt of s117 aftercare.

Literature and Evidence review

Section 117 Aftercare

In accordance with relevant legislation (The Care Act 2014), the 'right to have' a PHB has become legally mandated and is designed to provide access to a fair yet personal standard of continuing healthcare to individuals who meet the criteria. Since December 2019, PHBs for mental health have become exclusively available to people who are eligible for aftercare under Section 117 of the Mental Health Act. S117 aftercare commences once an individual who has been detained under relevant sections of the Mental Health Act leaves inpatient care; lasts for as long as it is needed to prevent a deterioration in the person's mental state, and; can only be terminated if this is deemed appropriate following a review of the care plan by the relevant Commissioning Support Unit (CSU) or Clinical Commissioning Group (CCG), only with the agreement of the relevant local authority. Though the National Health Service is mandated to provide support for people who meet the specified criteria, receiving aftercare is not compulsory and can be refused if this is in line with the wishes of the individual (Andoh, 2005) ensuring that personalisation is present across all aspects of the PHB and is compliant with ethical guidelines pertaining to consent to engage with services post-discharge. Due to its recent implementation, evaluations of PHBs for mental health are largely limited to pilot sites, with the majority of current budget-holders being among the first cohort of individuals to receive a s117 PHB since its inception.

Evidence on mental health inequalities has consistently reiterated that people from black and minority ethnic communities are disproportionately detained under the Mental Health Act (Cabinet Office, 2018; Department of Health and Social Care, 2019; Bignall, et al., 2020) and upon discharge, disproportionately reflected in the number of community treatment orders issued (Gajwani, 2016). Based on existing literature, it is clear that this phenomenon is likely to be the result of a complex amalgamation of longstanding institutional and structural racism, and a systemic misunderstanding and disregard of racial and cultural practices, which has often resulted in a widespread incapacity to engage with people from black and minority ethnic communities, some of whom, have come to exhibit a marked mistrust of formal mental health services (Vahdaninia et al., 2020). Consequently, the

introduction of PHBs presents individuals from black and minority ethnic communities, who have long since desired greater independence and autonomy over their mental health care, a feasible compromise, whilst still retaining access to support from established mental health professionals and networks offered by conventional care provision.

According to Disability Rights UK (2017), no official distinction between what constitutes a health care need and what constitutes a social care need exists. For people with mental health difficulties, this grey area can often be even more confusing to understand, particularly if they are receiving an integrated budget for their care. To address this, DRUK have reiterated the necessity for regular revisions of the support plans which accompany PHBs, in order to take account of changes in the health needs of the budget-holder and clarify what the budget is being spent on. In agreeing to undertake this practice frequently at the outset of the PHB journey, professionals can ensure that expectations on both parts are well-managed, and that budget-holders are provided with clear, consistent information that is accessible and that reduces burden, as opposed to producing it. To date, this practice has been shown to be either largely absent or ineffective, particularly among people from black and minority ethnic communities, with existing literature indicating that whilst limited choices for the personalisation of care (both cultural and otherwise) serves as a significant source of frustration, this is secondary only to the more concerning core issue; the persistent lack of communication regarding support options, in a format that is understandable (Memon et al., 2016; Williamson, 2020). Due to the complex nature of information communication and challenges presented by mental health difficulties in the specific context of black and minority ethnic communities, it is likely that cultural brokerage, which has been shown to be largely successful as a good practice for access and wellbeing (BME Health Forum, 2010), is one of a limited number of viable options, though the potential for this as a means of improving the experience of PHBs among people from black and minority ethnic groups has yet to be explored.

Additionally, a report by NHS Confederation (2011) found that personalisation offers and facilitates independence and agency with regards to choosing treatment and support options and this is largely considered a benefit of the approach. However, both budget-holders and carers have expressed a fear that this degree of freedom

may be a potential risk for increasing the pre-existing lack of representations of people from black and minority ethnic communities in referrals for low-intensity, clinical mental health interventions such as talking-therapies. Likewise, evidence has shown that a number of mental health practitioners have suggested that people with chronic mental health problems may be incapable of managing social care personal budgets and consequently making the decision (Carr, 2010a; Taylor, 2008), in some circumstances, to encourage them to opt for a lesser degree of personalised care (Carr, 2010b). In spite of this, more recent research has suggested that PHBs could produce improved outcomes for people from certain groups such as those whose needs have been poorly served by conventional mental health services which largely includes people from ethnic backgrounds and those who have mental health problems (Department of Health, 2013).

Personal Health Budgets

Following on from success in many developed countries across the globe (Health Foundation, 2010), Personal Health Budgets (PHBs) were piloted in England to support people living with long-term physical health conditions between 2009 and 2012, before being nationally introduced in 2014. Evaluations of the pilot programmes demonstrated that people with PHBs showed lower levels of use of other NHS services, including in-patient care, than people who did not have a PHB, with the average difference amounting to £3050 a year for those with mental health problems (Forder et al., 2012). Furthermore, the outcomes for PHBs were largely positive across a range of domains, including impacts on health and family, with a number of budget-holders also reporting advantages supplementary to main condition for which the budget had been awarded (Davidson et al., 2013). The general consensus has been that PHBs are a step in the right direction and have provided an example of how existing healthcare funding can be modernized in order to meet the needs of the individual more effectively.

Though predominantly focused on health, it has also been acknowledged that there is a unique and indisputable need for the support of the Voluntary Community and Social Enterprise (VCSE) sector in ensuring that PHBs are fit-for-purpose and enduring. The knowledge, connections, skills and experience offered by these organisations can provide a powerful foundation for partnership, though there has also been disclosures of discrepancies between CCGs in their strategic approaches

to addressing the needs of the individual (Voluntary Voices, 2018), it is vital that both adopt a complimentary and collaborative style of working, particularly as many people from black and minority ethnic communities rely heavily and somewhat equally on both in order to manage their mental health needs.

Following a consultation in 2018, the decision to expand the remit of PHBs was confirmed and in December 2019, the right to have a PHB for people who are s117 eligible was introduced. Prior to this, there was an absence of a specific and robust form of personalised care for people with enduring mental illness within the healthcare sector. Under previous provision arrangements, adults with mental health difficulties which were independent of a formally-diagnosed physical health condition were ineligible for support under the category of 'continuing health care', as they often did not display a level of care needs that required direct nursing-based interventions (Alakeson et al., 2016). Evidence such as this has highlighted the extent to which people living with 'hidden disabilities' such as mental health difficulties have been largely overlooked, with people from minority ethnic groups commonly experiencing a double disadvantage in comparison to people from White ethnic groups (Judicial College, 2013).

A report by The Health Foundation (2010) focused on providing learnings from personal budgets for adult social care that could be shared across the health and social care sectors. The authors found that black and minority ethnic people showed reduced levels of engagement with direct payments and personal budget for adult social care schemes. In addition, people from these groups were also shown to be more likely to employ a friend or relative to undertake an informal carer role as a matter of preference, rather than accepting care staff offered by the NHS and external care and support agencies, providing a potential justification for why they are also generally less likely to observe positive changes in mental health service provision (Vahdaninia et al., 2020). These findings are critical to consider in the context of the PHB design and rollout, as they offer a valuable focal point for understanding how health commissioners can complement the work of the social care sector to best address existing health inequalities that affect people from black and minority ethnic backgrounds. Furthermore, recent literature has also advised that more reviews of existing roll-out are required to ascertain potential

recommendations and revisions ahead of wider implementation (Anderson et al., 2020).

Recommendations from existing literature have chiefly focused on encouraging healthcare commissioners to develop and strengthen services which take holistic, flexible approaches to support provision which accounts for the family context and cultural needs and has led to an increase in the uptake of personal budgets for adult social care amongst individuals from black and minority ethnic backgrounds (Carr, 2011). For their systematic review, Webber et al., (2014) screened more than 17,000 studies on the effectiveness of personal budgets within adult social care for people with mental health problems and found that very few specifically mentioned and/or focused on people from black and minority ethnic communities, leading them to conclude that outcomes for people from these groups remain significantly unrecognised and warrant further exploration. ***To date, no specific evaluation of mental health PHBs or PHBs for black and minority ethnic communities has been conducted; a knowledge deficit that this small study begins to address.***

Evidence from Forder et al., (2012) has suggested that comparatively few people from black and minority ethnic communities have been recruited to PHBs than people from white majority groups and to date, we have found no studies or evidence to suggest that this situation has changed. This is likely to be a result of information about available support options being extremely limited and some individuals not being fully aware of what is on offer to them and how the offered provision is capable of meeting their full range of needs, as has been highlighted by several recent studies (Mind, 2013; Penfold, 2016; Regmi et al., 2017). The auxiliary impact of this is reduced engagement with NHS services and an increased demand on largely underfunded VCSE organisations, potentially culminating in the need for repeat hospitalisations, emphasizing the need for a more visible NHS commitment to constructive working with the voluntary sector, community sector and faith groups (Bignall et al., 2020).

Intersectionality and Mental Health Inequalities

Socio-economic deprivation

In the UK, figures continue to demonstrate that the likelihood of experiencing deprivation is directly associated with ethnicity (Office for National Statistics, 2019a). Furthermore, the likelihood of experiencing severe and/or enduring mental health difficulties is also associated with ethnicity, but is largely mediated by deprivation. Individuals from black and minority ethnic groups are more likely than the White British population to be deprived of statutory, preventative mental health support that enables them to avoid crisis in the first place. They are also more likely to experience substantial barriers to access suitable, alleviative mental health provision which renders them more vulnerable and at an increased susceptibility to deterioration or repeat detention under the Mental Health Act. This has been evidenced by recent findings in the Five Year Forward View for Mental Health (Independent Mental Health Taskforce, 2016), and further supplemented by the conclusions of the Independent review of the Mental Health Act (Department of Health and Social Care, 2019) and the Racial disparities in mental health literature and evidence review (Bignall et al., 2020).

Birmingham has been identified as being one of the UK's top ten most deprived regions (Ministry of Housing, Communities and Local Government, 2019). Areas of deprivation also largely overlap with wards that have a high population of people from black and minority ethnic backgrounds (Cangiano, 2007). Publications by the World Health Organisation (Friedli, 2009) and the UK Department of Health and Social Care (2019) have provided evidence that reiterates the significance of deprivation as a risk factor for mental health difficulties. Many people who have experienced difficulties with their mental health and have repeat hospitalisations have observed cuts to local, culturally specific services, in lieu of a more centralised, clinical model of care (NHS Confederation, 2011). This further increases the health inequalities, defined as "Socially produced, systematic differences in mental health between social groups that are avoidable and therefore unjust" (Mental Health Foundation, 2016). The aim of the PHB should be to ensure that people from black and minority ethnic backgrounds are accurately and effectively represented not just within the system, but are also consistently integral to its design and evaluation in

order to eliminate the disparities caused by traditional approaches to mental healthcare.

Factors Impacting the mental health experience of black and minority ethnic people

In line with the objectives of the recent NHS Long Term Plan (NHS England, 2019b), PHBs have been revised with the intention to benefit up to 200,000 individuals who utilise mental health services by 2023/24, though this expansion is still in its preliminary stages. The definition of s117 aftercare as introduced by the Care Act 2014 defines the right to have as including support that considers an individual's mental health needs as encompassing their social, cultural and spiritual needs. This delineation has been considered long overdue, particularly as literature has indicated that people from black and minority ethnic communities have had longstanding difficulties with provision due to a range of factors including but not limited to, a lack of intercultural understanding, lack of suitability to needs, mistrust of professionals and stigma surrounded engagement with services (Chantowski, 2014; Department of Health and Social Care, 2019). These difficulties, coupled with challenges to accessing information concerning health and wellbeing services and the historical absence of options for personalisation (Malbon et al., 2019) that matches personal and cultural expectations, have served to reinforce existing inequalities.

The lack of cultural appropriateness within mental health support services has been frequently cited as the primary cause for the dissatisfaction and subsequent reduced uptake of this provision among people from black and minority ethnic backgrounds. Informal social structures, particularly in the form of support from family and friends has long been a source of support that can often be perceived as a more favourable alternative than engaging with formal mental health support services (Silveira and Allebeck, 2001; Memon et al., 2016) although research has also shown that some black and minority ethnic individuals are also more likely to avoid support-seeking altogether, in favour of going it alone (Arday, 2018), possibly a consequence of poor past experiences.

There have also been difficulties evidenced in recruiting a sufficient number of Personal Assistant (Pas) to meet the required cultural needs and expectations of older people from black and minority ethnic communities (Glendinning, 2012). Although Personal Budgets in social care and Integrated Personal Budgets for health

and social care needs are designed to be used for effective and appropriate services, for black and minority ethnic individuals the scope of services that can be classed within this criteria has been exposed as being extremely narrow and lacking sufficient breadth or depth to positively impact the mental health of the people that use them over the long-term (Moriarty et al., 2011; Greenwood et al., 2014). Despite the fact that much of the existing knowledge of personalisation is derived from reflections on personal budgets within adult social care, it is clear that these shortcomings may also pose a substantial risk to the efficacy of s117 PHBs if early action is not taken to adopt key learnings and incorporate the recommendations from reviews of existing health and social care provision.

According to the 2011 census, approximately 20% of the UK population is from a black and minority ethnic background (Office for National Statistics, 2019b) and within this sub-population, 80% of people describe themselves as belonging to a religious group, in comparison to 65% of majority White population (Office for National Statistics, 2019c). Lack of capacity to provide mental health care that is both sensitive to and caters for the socio-cultural requirements of people from black and minority ethnic groups, including ethnic and religious has been a longstanding and extensively debated matter of contention in black and minority ethnic mental healthcare research (Mental Health Foundation, 2019). Addressing the holistic needs of black and minority ethnic individuals, including the intricate aspects of their religious and cultural needs has been highlighted as a key recommendation for designing treatment and interventions that are culturally appropriate for people from black and minority ethnic backgrounds (Mental Health Foundation, 2019).

Existing literature has also demonstrated that having the knowledge and confidence to articulate personal needs is also a key issue for people across several black and minority ethnic backgrounds. This particular experience has been largely attributed to communication/language challenges, as well as difficulties in negotiating the “structural and bureaucratic obstacles” in mainstreams services acting as an additional barrier to successfully engaging with services in the way they desired (NHS Confederation, 2011). From this, it is clear that the details of health systems are communicated in a way that is accessible to service users from black and

minority ethnic groups is essential, as a lack of information can lead to groups feeling ‘locked out’ or marginalised by the very services that have been created to serve them. Ultimately, research has also proposed that additional work is required in order to strengthen the voices of black and minority ethnic people and their efforts to obtain mental health care that surpasses adequacy and becomes fit for purpose (Chantowski, 2014).

Additionally, an early review of PHBs by service users and carers found that people from black and minority ethnic groups have a strong desire for access to more local, culturally appropriate services that are grounded in the understandings and practices of their own communities, as opposed to the generic or large-scale services being offered and managed by mainstream providers (NHS Confederation, 2011). Literature has suggested that an evidence-based way to address this challenge is to work in close partnership with the non-statutory sector. Despite presenting a potential impediment to larger organisations and institutions, empowerment of black and minority ethnic people and providing ongoing support for the management of their needs is often where VCSE organisations tend to thrive, with the benefits of their cultural familiarity, competence and experience reinforcing their skills and organised approach, particularly those that are led by people from black and minority ethnic backgrounds and delivered at local and regional levels (Butt et al., 2015). These findings have been supplemented by the subsequent review of how the VCSE sector can be effectively mobilised by the health services as a key contributor to wellbeing, health and care (Department for health and Social Care, Public Health England and NHS England, 2016). Thus, in order to determine how to accurately assess and address potential disparities faced by people from black and minority ethnic communities with regards to their continuing mental healthcare, it is imperative to explore the insights provided by the feedback on the personal experiences of people from across these groups and formulate an understanding of how they connect different sources of support in order to personalise their health and wellbeing.

Methodology

Scope of the literature and evidence review

The scoping literature review is designed to identify relevant papers and studies in order to extract and evaluate key findings on which the structure for the current study will be based. The literature review was conducted using scoping methods which adhere to Arksey and O'Mally's framework (2005) and CRD guidance on systematic reviews (2008). This consisted of using a pre-defined set of key words and thesauri variants to inform searchers, in addition to using general broad-base terminology and free-text terms in order to maximise search engine and database coverage. These terms were combined to form a range of phrases using the standard Boolean operator terms; AND, OR, NOT, AND NOT. The list of keywords/key terms used to gather and assess the suitability of evidence is shown in the table below.

Race, Ethnicity and Culture	**Mental Health and Psychosocial Wellbeing**	**Health-based concepts**
Asian BAME Black Black and minority ethnic BME Culture/Cultural Ethnic/Ethnicity Minority Ethnic Mixed-race/Mixed-ethnicity Race/Racial	Belief Emotional Mental health Psychological Religion Social Spiritual Wellbeing	Continuing healthcare Detained/detention Mental Health Act NHS Personal health budget Personalisation Personalised care PHB Section 117 / s117

The primary focus of the literature search was to identify existing evidence in this area of research that has been conducted over the past 10-year period (2010-present), in line with the expeditious switch in focus to personalisation in healthcare as evidenced by its rapid increase in prominence within the literature (Ferlie, 2018; Silander et al., 2020). This facilitated the development of a brief series of relevant research questions in an iterative manner and allowed for the focus on how personalisation and personalised care has impacted the mental health journey of people from black and minority ethnic communities who have previously been

sectioned under the mental health act and who are currently under the care remit of an NHS community service.

Interviews

In line with the aims and objectives of the study and the evidence obtained from the scoping literature review, a semi-structured topic guide was created. This guide included themes such as knowledge of PHBs, lived experience of mental health and illness, religious and spiritual beliefs, ethnicity, culture and mental health, community and familial support, activities of daily living, views on personalisation and tools for resilience/coping mechanisms. The topic guide was shared with the project team for review and input prior to the start of all interviews.

The initial project aim had been to invite between 20 – 24 participants to take part in three focus groups in order to retain a small yet robust sampling frame that is diverse enough to reflect the PHB and mental health experiences of a wide array of people form black and minority ethnic groups. However, due to challenges with recruitment, the design was altered to encompass one-to-one interviews which focused on the subjective lived experience of a limited number of participants. The benefits of this approach included an elevated level of profundity due to the details shared and increased scope for clarification, as well as the absence of external influence of professionals or peers, enabling participants to share their experiences in their own words without concern for the input or judgement of others.

Interviews lasted between 35 and 70 minutes and were audio-recorded once consent had been obtained from each participant. A £25 gift card as ‘thank you’ was given to each participant as a token of appreciation for their participation. Travel expenses were also reimbursed to participants as necessary.

In order to analyse the interview transcripts, a Framework Approach was used. This process included an initial familiarisation with the data during the initial transcription process, the identification of core themes and subthemes, in addition to a context-grounded interpretation of the data which rooted conclusions primarily in quotations from participants, which were further supported by the findings of existing literature. Each participant was assigned a pseudonym during the transcription process as a means of ensuring anonymity.

Participants

Three people were recruited to take part in the project from across Birmingham and Solihull NHS Foundation Trust and the East London arm of the Advocacy Project, a charity that serves people from marginalised communities and operates across a number of locations.

Overview:

- 2 female, 1 male
- 2 Black British (Caribbean), 1 Black African
- 2 Birmingham residents, 1 London (Hackney) resident
- Aged between 29 – 58
- All spoke English as a first language

Each interview was initially played through and transcribed. On the second replay, notes were made from the transcripts on all concepts discussed and each concept was placed under one or more of three categories; (PHB-specific, Mental Health-specific or Other conversation). Time stamps were also added to aid subsequent locations of exact quotes.

Concepts were placed together into groups based on key words/synonyms/common topics that linked them. Concept groups were then compared for similarity in the same way as the individual concepts within them and placed under major headings. The concept groups went on to become the subthemes and the major headings became the main themes. Not every subtheme applied in equal measure to each participant. Certain subthemes were more pertinent to the lived experience of some of the people who took part in the project in comparison to others.

Successfully Navigating the Personal Health Budget System

Knowledge and Understanding of PHBs

We asked participants about the details of their PHB including if they were aware of the type of budget they had (both budget type and payment type), whether they had knowledge of the exact amount of money they were entitled to, the frequency of payment and their recollections of timescales from the moment of finding out they were eligible, to receiving the funds/services.

One participant, **B,** shared that she was not told that there are different types of PHB and said that it would have been helpful to have been told this at the start so that she could have considered how she wanted to spend the money in a bit more depth.

For another participant, **M**, it was often very challenging to explain the complexities of receiving benefits from both health (NHS) and social (Local Authority), particularly as she is required to provide evidence of limited income in order to ensure that her daughter continues to receive free school meals and is cared for.

Additionally, **W** expressed his gratitude for being allocated a support worker who was able to clearly explain how the PHB system worked and support him through the entire process. This meant that he and his support worker had already discussed what the budget would be spent on and which needs it would be able to address during the waiting period, and so were able to get things moving quite quickly once the money had been received.

[Int] What difference do you think it would have made it to you if someone had sat down with you and explained to you how much money you would be getting?

[B] I would have been very glad really cos I could help myself a bit more…It wasn't easy to understand, no. I don't even know, when you said personal budget, it sounds like I've got to budget my money. It's very hard to understand… I don't know it's the way they word it. If they was to make it sound like "BE, you get £400 a week for somebody to look after you in the house or something like that. When you say personal budgeting, you don't really understand a word. It doesn't really make sense or nothing. If they was to make it more clearer. They can keep the same wording but explain it more clearly."

[Int] Do you know about the different types of personal health budget or do you know what type of Personal health budget you have?

[M] "I think I have one related to disability. I'm not sure whether I'm medium high or low. It's definitely not a low one. It could be a medium one but I'm not sure necessarily. But I would normally say tick high because I can't… I'm… I find it very hard to speak and apparently, I'm going deaf and my father, he was going deaf, but he wouldn't do anything about it. But I've decided that I'm going to do something about it because I didn't really want to wear a hearing aid and I do feel a bit stupid, but I can't hear sometimes when I'm eating."

[Int] So do you remember when you got your personal health budget? Was it recently?

[W] Yeah, it was in February [2020] … but we'd been applying for it since a while back. In July [2019], I think.

[Int] Did they give you an amount upfront of how much you would be able to use?

[W] Well, I wanted to do Jiu-jitsu but it's quite expensive, about £110 a month. So, what happened was they gave me three months' worth and then, with the kimonos they gave me £580 which I just paid straight to the account then I was able to start.

[Int] Did you have to wait when you left hospital to find out about it?

[W] If it was something that was offered when you leave hospital, if it was offered and it was well-guided… Cos sometimes you're out of hospital and then you're just on your own so you know you've got something in place when you come out. I didn't even hear about it. I only heard about it months after I left hospital… I found out about it through my support worker, she's amazing.

[Int] Do you think the information provided by the NHS about Personal Health Budgets is clear and easy to understand?

[W] I didn't read it (laughs).

Based on these three one-to-one interviews, it is possible to conclude that there is more to be done to ensure that recipients understand what a s117 personal health budget actually is. Although NHS staff may have explained this previously, it appears that it may not have been understood or may have then been forgotten. With no written resources available as a point of reference, the lack of understanding may be compounded as has been evidenced in the literature (Peate, 2012; Memon, et al., 2016).

Also, the timeline of the PHB process from discharge and application to receipt of funds and/or services requires further clarification. As one participant mentioned, a period of approximately 9 months elapsing between applying for his PHB and finally receiving it that caused him to question how others would manage were they to be in a similar position with a higher level of need then him. In line with adopting a transparent and informative approach, it would be useful to discuss key milestones in the journey from the initial stages (being informed about eligibility and commencing application) to latter stages of full independence (the ongoing budget and support plan reviews).

Drawing on these conclusions, we are recommending that in order to ensure every individual knows and understands what they will be getting, a clear, jargon-free verbal explanation of the 3 main types of health and social care budgets (Personal Health Budget, Personal Budget or Integrated Personal Budget) and the 3 payment types (Direct payment, Notional Budget or 3rd party payment) PHB is necessary at every initial appointment (which should take place as soon as possible post-discharge), and may also need to be explained again at a later point to ensure that people understand exactly what type of budget they have.

Additionally, a physical, hard copy document that re-iterates this explanation in an Easy Read format should be distributed following every initial appointment so that all budget holders can take it away and read through it with their trusted associates (support worker, friend, relative etc) in their own time. The timing of this information is also key, as this will affect how much of it people are able to understand and retain therefore consideration must be given to when it is appropriate to have discussions concerning the details of PHBs. Based on this finding, it may also be necessary to provide interpretation and/or translation service during appointments as required, in

order to reduce the impact of potential language barriers often experienced by people from black and minority ethnic backgrounds in accordance with best practice guidance as highlighted within existing literature (Arafat, 2016; Uwakwe, 2017).

Impact of Carer/Key worker support

When talking about individuals who provided help and support about matters relating to both PHBs and mental health, all of the individuals mentioned one or more professionals (i.e. a support worker or care coordinator) whom they interacted with regularly and who possessed the knowledge and skills to help them.

As **B** discussed how she utilises the weekly hours that she has her carer for and how her carer helps her during this time, the positive impact of having a carer that is paid for by her PHB became more apparent. The assistance provided by her carer includes a mix of at home and day centre support, as well as help with physical support (personal hygiene, cooking, light cleaning) and psychological support by providing company and verbal encouragement. **B** believes that having a carer visiting her at home regularly is best thing about her PHB.

For **M**, reflecting on how her carers have worked to support her in the past and why it is important to her to have a carer was a focal point. Although her daughter also provides informal care and support in the house when needed, she does not feel that it is right to burden her daughter with the responsibility as she is young and still studying.

W shared how the help of his support worker both past and present has been extremely helpful. His support worker has taken the time to explain all of the information to him in a way that he can understand and always keeps him updated. He is also comfortable to ask her if he is unsure or would like to make any changes.

[B] *"I have somebody 3 days a week come out to see me and I've got 12 hours. That's what they allowed me to have. 12 hours for the week so I break that down into 4 hours a day. And they do, um, they help me with my shower, 'cos I find I'm not really motivated to do much, my medication makes me very tired and sleepy and if, if that lady, if my carer wasn't coming out, I normally spend most of my time in bed all day. Not motivated to do nothing and then very down, very depressed, very stressed out, no hope in life or nothing at all so she makes a difference. Someone to come and look forward to come to the house and I'm very lonely. Very, very lonely. Very depressed. Very downhearted, it's not a nice experience at all. I don't get no visitors or things like that. My mum will ring me every day, but I hardly get any visitors and when she's gone, then I spend, I just go back to my bed. I spend most of the time in my bed… She's very helpful."*

[M] I appreciate it because when I was in hospital and I got knocked down and stuff... they cook my dinner and I can't even get a bath very often so they run my bath and my daughter will come along to help me get out the bath naked so I do feel a bit stupid then.

[Int] Does your daughter still help you to do that now?

[M] No not anymore not, I want her to be getting on with her thing because she says feels she's a big woman and she shouldn't be doing it because at her age, I was certainly telling my mother what I think I need to do and what she wasn't listening to, to me, so I tried to open my ears and listen to what she has to say, think about it and go well, there's no carers tomorrow on Friday, that's right, and you have a half day on Friday, perhaps you can come with me? She's gonna go "no, have a half day on Friday because I want to study. Perhaps we can go on Saturday morning?" And I might go "ok ok" and instead of going no problem she never says no problem, she says no worries and hearing no worries compared to no problem is a better thing for me.

[W] When I left the hospital, me and my girlfriend had a fight, not a physical fight and then yeah, I learned a really hard lesson. Yeah and then I got a lot of support from Support Worker Name so, I still see [her].

[Int] If you were unsure regarding anything related to your personal health budget who would you go to to get information or help?

[W] (Support worker's name) … she's really good.

Considering the information from all the accounts it is possible to conclude that having a carer provides them with reliable practical and emotional support in carrying out tasks and activities of daily living that, when left undone, may lead to stress or anxiety which causes mental health to deteriorate further. Hence, the presence and work of the carer supports mental health indirectly by reducing negative mental states, but also directly, through the provision of less tangible benefits including company, reassurance and encouragement.

Using a PHB to fund hours for a carer to come into the home and provide support or accompany a budget-holder to attend events that they are interested in outside of the home appears to be a very significant aspect of the PHB as a whole. It is possible that this may be linked to, and supplementary of, the informal caregiving role that is often provided by family and friends within black and minority ethnic Communities. Therefore, understanding how to integrate the role and capacity of the carer into other aspects of PHB use (i.e. encouraging skills for independence, signposting to services and creating a feedback loop between the carer and the NHS care co-ordinator) is key and will allow the PHB to run more smoothly and also help to identify areas that may potentially lead to relapse if unaddressed more quickly.

Going forward, the recommendation is to ensure that this support is widely accessible, and that it can be provided by carers and practitioners from a wide range of cultural backgrounds that are reflective of the communities they work with, as this is likely to increase relatability and subsequently engagement. It may also be beneficial to incorporate ways service providers are working to address such experiences in the PHB literature in order to encourage a better take-up.

Scope of spending budget

When discussing what they had spent their budget on, a range of products and services were mentioned. Despite being largely content, some participants expressed that their budget had not covered specific things that they wanted and had hoped for, particularly in terms of expenses when travelling to visit family or courses to help them become more integrated into their community.

The main challenge/disappointment shared by **B** was not being able to use her PHB to visit family and friends, both locally and in different parts of the UK. Although she feels that this would be a good way to boost her mental health and wellbeing, she has accepted that financial restrictions are limiting her capacity for travel as she requires money specifically for cab fare due to not being confident in travelling on trains.

M was very happy that she has been able to utilise her PHB to purchase appliances for her home that make her activities of daily living easier/more convenient. She has noticed a direct improvement to her mental health as a result of this and believes

that this will also lead to an improvement in the quality of life for both herself and her daughter. She has also used her PHB to help pay for courses at her local Recovery College where she feels at ease because she feels comfortable to just be herself whenever she is there.

Conversely, **W** has accepted that there are certain things which may influence his mental health that his PHB cannot be used to pay for directly, such as visiting his family who lived abroad, however, he is very much interested in using his PHB to fund access to courses and training that will equip him with specific skills for employment so that he can make a living. In having a job, he will be able to save the money he needs to fund trips abroad so that he can visit his family and loved ones, resulting in an improvement in his mental health.

[B] "I did ask them if I could go and see my daughter all the way in Solihull, but they said no."

[Int] Who's "they"?

[B] "I don't know. They did wrote and they said that… I dunno if they were running out of budgeting or what cos I didn't have much going, but they said they wouldn't be able to cover that."

[Int] Is there anything that you have interest in that they don't have maybe?

[W] I'd like to do an interpreting course.

[Int] That would be really interesting, why interpreting?

[W] Umm, cos I've done, I do it all the time informally, but I would like to do it on a professional level because I'd be helping people and I'd be getting paid and its flexible… If I had the translating course, then I would be more integrated into the Portuguese community.

[Int] Was that one of the options on the app?

[W] Ummm… I think, I don't think so… I think there's stuff like training on the app.

[Int] Are there any things that affect your mental health that your Personal Health Budget doesn't cover?

[W] Ummm (laughs) yeah.

[Int] Is it a lot of things, is it some things…?

[W] Ummm. Some things yeah.

Generally, participants expressed that there were a number of challenges in implementing the budget once it had been received. For example, there had been desires to utilise the budget for certain activities, such as day trips with family, that

had not been approved. This disappointment was compounded by limited communication from care co-ordinators regarding dealing with unmet expectations of services or provision, which had led to further feelings of disappointment. This was also linked with a lack of knowledge and understanding of PHBs in general, with discrepancies between the expectations and reality of the scope of the budget being the leading cause of dissatisfaction with PHBs among all participants. As all participants were receiving their budget from PHB pilot sites, it is anticipated that these sites will be engaged in ongoing review and learning from experiences to improve their provision.

The scope of the budget should be on the agenda for discussion at the first appointment when PHBs are introduced to potential budget-holders. Ensuring that all individuals receive information that is clear, concise and consistent is of critical importance. This is of particular relevance to people from black and minority ethnic backgrounds, as evidence has repeatedly shown that a lack of understanding of services and lack of confidence in accessing them is a significant precursor to disengaging with mental health services across several black and minority ethnic communities.

Managing and editing the budget

When asked to consider how they had been managing and keeping on track of the details of the budget and payment systems, and how they might make changes to their budget payment type if this was desired, participants responses were mixed. The aim of this discussion was to ascertain whether personalisation also extends to the management of PHBs, in addition to the focus of the direct support provision they cover.

B shared that she found it challenging to keep on top of the expense system used for her PHB which requires her to spend money first and reclaim the funds back by sharing receipts for each spend. This is difficult for her as she is not always able to get a receipt which ultimately causes her to become more stressed due to knowing she may not be able to claim money back for day-to-day expenses. She would prefer to use a different system, but she is not clear on how she could make changes to her PHB in order to do this.

M shared that she feels content that other people are involved in co-ordinating her budget and her care as she believes that they know more about her needs and how to allocate her budget than she does. These people include her daughter and professionals that she has worked with both previously and currently.

W likes the digital nature of the PHB system as he finds it easy to use. He also likes that things have been grouped into categories that make it easier for him to search through and find things easily. He did, however, recommend that using an actual app, as opposed to an online website would be a better interface for people who were able to manage their PHB through their phones.

[Int] Do you feel like you had a lot of say in choosing the budget type that suits your needs the best?

[M] Um I think other people knew about what my needs and budgets and desires were before I even got to the interview.

[Int] Who are the other people that you say know more about your needs?

[M] My previous social workers, previous support workers previous caregivers previous friends previous colleagues previous people I've met in passing.

[Int] Anybody that you interact with now?

[M] Yes – my Occupational Therapist. I knew her from back in the day when she worked at the day centre and she wasn't my support worker, but she definitely knew my case and my daughter well and she's definitely one sort of person who I just trust her. I say ok fine, as it's you, it's ok, it's fine with me.

[W] It's like an online bank thing, an app that you log on to. You go online and you log onto it then it's there like a credit card and then yeah, then you can make payments, you can set up direct debits, you can make one-off payments… yeah so they have things like for gifts, they have these options there and I was thinking rah, okay.

[Int] Do you think you'll use your Personal Health Budget to do anything else apart from Jiu-Jitsu?

[W] What, will I apply for something else? Yeah possibly.

[Int] So you mentioned the app, how user-friendly do you think the PHB system is from start to finish?

[W] It's straightforward to use but if you had an actual app it would probably make it easier.

[Int] How would you rate the straightforwardness on a scale of 0 to 10 with 10 being the highest?

[W] I'll give it an 8.

In sum, having the freedom to choose whether a PHB is managed completely independently (Direct Payment), with support from an NHS professional (Notional

Budget), or with support from a professional from the voluntary sector (Third party Budget) or a mixture of one or more of these provided participants with greater flexibility. Even though participants differed in their budget management type, each of them had a good understanding of what their budget was being used for and how much goods and services cost. This demonstrated a good level of involvement.

Our recommendation is to ensure that following budget allocation, all budget-holders are provided with a verbal explanation of how to personalise their budget, for example, change their budget type (from direct payments to notional budget or vice-versa), in addition to an explanation of the process for making changes to the provisions they have chosen for their budget to cover (i.e. swapping personal care for gym membership). This is necessary as some participants stated that they would not know how to change the way their budget is spent even if they wanted to, which could lead to the perception of lack of agency and access to information that has been shown to precede disengagement with services by people from black and minority ethnic groups (Memon, 2016)

Personalisation

Personal Responsibilities and the Role of the Family

We asked participants if and how their personal health budget impacted on their family and/or family life and what this meant for them. In considering how aspects of their care made a difference to the people around them, they offered some very insightful evaluations of how their personal responsibilities influenced the way they chose to utilise their PHB.

B has responsibilities for her adult daughter who also has mental health problems and is currently an inpatient in a mental health facility that is far away. Not being able to support her daughter negatively impacts on her mental health and being physically distant from her daughter also negatively impacts on her mental health.

M's role as a single mother with a teenage daughter means that she must ensure that she utilises aspects of her budget to look after them both. She also expressed anxiety about feeling the need to inform her daughter's school about how much money she receives for her PHB and other benefits so that her daughter's Free School Meals are not affected.

Though **W** lives in the UK, he was born abroad and has family in various countries around the world. He must make sure that he looks after himself and is also able to contact/travel to meet family so must budget for this. Whether or not a PHB could be used to (part) fund a trip is not clear and has not been discussed.

[B] "Plus what gets me down as well I've got a daughter who's 39 years old and she's suffering with mental illness and they've put her into a um… into a hospital all the way in Solihull and I find it very hard to get there. I don't visit her 'cos it's too far and I don't know how to get the bus or the train and things like that. Well, one thing they've allowed, they've just recently allowed her to come one night per week. She'll come in a taxi 'cos she can't take the bus at all, so they allow her… she comes and makes her way in a taxi, comes on the Friday afternoon and then afterwards she goes home in a taxi on the Saturday."

[M] "I'm unable to prove my income because my daughter gets sponsored. So, she gets Free School Meals and I've got to show them how much benefit I had come into my account so that they can see it wasn't earned money. But the money I'm getting is my PIP, which I only get once every three months or something like that."

[Int] How much control do you feel like you had, or you have over your personal health budget?

[M] Oh my daughter makes a lot of decisions... she makes a lot of decisions and I try and trust it.

[Int] Are you happy with the fact that your daughter makes a lot of decisions for you?

[M] Sometimes I'm very happy with the decisions she makes for me especially when it comes to hunger cos I have this thing where she says I have an eating disorder and I believe her now and I believe I have got an eating disorder now because if I can't get to what I really want which is a nice glass of fizzy 7 Up then coffee will do.

[W] My Dad lives in Bolton and my Mum lives in Portugal with my brother.

[Int] Does your Personal Health Budget cover trips?

[W] No

[Int] Would you like it to?

[W] I think that's asking for too much!

Overall, it was clear that family played a big part in each of the participants lives. In every interview, family was the only concept that was referred to repeatedly and across different contexts. In addition, we also found that there was a clear link between monetary support and contact with family/family responsibility. Where the impact of having a PHB on household finances was also highlighted, participants were also receiving benefits and allowances for other things that led to confusion regarding exactly what the PHB is, how often it is paid, what it is for and how this differs to other forms of financial healthcare support was unclear. The impact of the perceived impact of mental health on the family and home is in line with findings from existing literature which has demonstrated the significance of giving parental care

and support whilst requiring mental health care and support that is magnified in many black and minority ethnic households (Greene, 2008), though this has been understudied in recent times. Due to the significance of family members as expressed both by participants and within the literature (Joint Commissioning Panel for Mental Health, 2014), it is recommended to include a relative or friend as a key contact who is encouraged to attend appointments and may be useful in terms of communicating information particularly with regards to changes to the PHB. The discussion concerning the potential impact of PHBs on state benefits was useful for gaining knowledge of how people understand their PHB, how it intersects with other types of support they may be receiving and what this means in terms of capacity to support one's family.

Greater flexibility with PHBs would ensure that individuals can stay connected with their family members ultimately resulting in a positive impact on their mental health. In order to address this, NHS care co-ordinators and key workers must provide clear delineation between whether or not the PHB can be used to cover certain expenses directly related to improving their mental health that are perhaps not classified under 'typical' goods or services. Evidence-based examples of this would include reimbursement of travel expenses for frequent visits to family, a practice that varies in significance depending on cultural expectations.

General satisfaction with PHBs

Though this topic had been indirectly addressed through feedback on other areas of the PHB, we recognised the importance of gathering clear feedback on participants perceptions of how content they are with their PHB and overall, how effective they believed their PHB to be in terms of addressing and reducing their personal struggles with mental health.

B is mostly happy with her carer and how her carer is able to support her most days of the week and rated her happiness with her PHB as being 7.5/10. She wants her PHB to fund her weight loss programmes and meals so that she can lose weight and feel more comfortable within herself.

Being able to use her PHB to cover both her wants and her needs has been a positive outcome for **M**. This has included purchasing appliances for her kitchen to help reduce the amount of housework she needs to do, particularly as this is

something she remembers being physically punished for during her childhood. Despite this, she still finds it challenging to explain how she is spending her budget to her family members.

The main challenge identified by **W** was the amount of time that it took between applying for his PHB and actually receiving the money. He believes that this may lead to some people feeling as though they have been discharged from hospital with no form of support if it takes a long time for them to receive their PHB.

[Int] On a scale of 0 to 10, so 0 is I'm not happy at all, and 10 is I'm as happy as I can be how happy are you with your personal health budget?

[B] Umm, I would say about 7 and a half.

[Int] So you said 7 and a half out of 10, why is it not a 10?

[B] Cos I'm not happy within myself, I'm still struggling with my mental health and the work is good, but I don't give it a 10 because ummm… I don't give it a 10 because I'm not happy within myself. And I'm still struggling with my weight as well, I've put on a lot of weight because of the medication and I wanna lose the weight so I'm not happy, I'm not comfortable.

[M] The personal health budget does help because when I decided to buy a dishwasher now because we used to get beaten very severely for not washing the dishes up after my mum had cooked the dinner when I was a child. This dishwasher has really saved my mental health from being so bitter and so self-absorbed and so worried about what do you think of body my daughter are you trying to do the best for her? I try to question those, that's always having my head.

[Int] So how would you describe having a personal health budget? What's it like for you?

[W] Oh, it's just amazing cos umm… for me it's really life-changing isn't it…

[Int] If you could suggest one improvement, do you have one?

[W] Um, yes, time (laughs) the timescales.

Overall, feedback regarding satisfaction with PHBs were very positive. All participants were largely happy with what they have been receiving to date and only had few areas for improvement. Some of the dissatisfaction stemmed from desiring greater level of personalisation, whereas in other cases, it was related to logistical issues which occurred in the form of delays caused by national challenges in the rollout of s117 PHBs. This is likely due to being part of the pilot PHB offer rollout, as it is anticipated that learning from budget-holder experience is ongoing at these sites.

As the primary concerns about PHBs were the time it takes to receive one and uncertainty regarding the scope of the PHB, this could be addressed by providing each individual with a summary card for them to keep that highlights key details regarding their PHB and who their key contact is, should they have any questions or queries. This is recommended as it would be effective for reducing grey areas in budget-holder understanding from manifesting between appointments, whilst also providing clarity and consistency for budget-holders and professionals if there are any changes in staffing or the nature of the budget. This serves to negate the risks of low-uptake and disengagement that would potentially occur as a result of lack of continuity.

Additionally, maximum and average timescales for the PHB application and allocation process should be introduced and shared with staff across the CCG that are involved in allocation and management of PHBs both directly and indirectly, as well as in an easy read digital and/or printed format for budget-holders, relatives and VCSE staff to have unrestricted access as required. This would facilitate the ongoing aim of shortening the time between applying for PHBs and receiving them in order to ensure that individuals discharged from hospital are supported and once again, ensure effective continuity of care as standard.

My Culture and My Mental Health: Expanding the Horizons of the s117 PHB

Ethnicity and Heritage

Racial and ethnic heritage were key aspects of each interview that were both highlighted by the interviewer and all of the participants. The discussion of “roots” and “culture” demonstrated not only how important these concepts were to the participants personally, but how important they believed them to be when interacting with people outside of their culture.

M also described a previous trip to Jamaica and talked about her experience of losing her suitcase and having to rely on a stranger to provide her with clothes and hospitality. Though distressing, it worked out well and she was very grateful, and this has caused her to think positively about Jamaica since returning back to the UK. The discussion also provided an opportunity for participants to reflect, with

After initially making a connection between his PHB and how this may be able to open doors for him in terms of training, **W** returned to the idea of undertaking an interpreting course and how this would allow him to become more integrated into the Portuguese community in London. As his mother and brother, who he is very close to, both live in Portugal, he views this as being very important to him.

[Int] Are there any changes you think should be made to the personal health budget?

[M] Maybe when they're talking to someone looking at their mouth and talking about where your influence is from and why that is about blah blah reh reh.

[Int] So sitting maybe with a Care Coordinator?

*[M] Yeah, 'cos I was telling them I met this young man actually and he said "My father's from Gambia", and I looked at him and I went that's why, that's the soul of our Jamaican culture and he goes, he looked at me like this (makes eye contact and nods) and he just went "You know what I'm talking about". And I didn't have to explain to this man at all and it was just really brilliant to be myself with a complete stranger instead of thinking they've always got to be a Jamaican cos they haven't always go to be a Jamaican. Nobody gives a s*** about whether you're Jamaican or not.*

[Int] So you think your culture is important in terms of managing your mental health and well-being?

[M] Yes. I like that poster (points to wall). It's quite clear that that there's some other cultured people around this area where people might get upset adopt out the insecurities and fears onto other people which is not their fault or not your fault. But I do that sometimes too and I think we all do that sometimes.

[Int] So at the moment do you see your family once a year?

[W] About 2-3 times a year. It really helps my wellbeing and I think the sun helps as well and then again that's me cos I'm Black and I happen to be from a Black umm, from a country that has you know, I'm blessed that Portugal has nice weather and that but then I don't know I'm thinking, tryna think of my brothers who are Ghanaian, Nigerian who don't really go back to Nigeria, maybe I don't know, it would be good for them to maybe visit your roots right, to see where we come from and where we're living and how our parents lived.

Expressing different aspects of their heritage and culture were useful in allowing participants to express how they felt about themselves and their background. Their understanding of this and their thoughts on others understanding and perceiving their heritage as important was a factor that they felt had a positive impact on their wellbeing.

Based on this, it is evident that having people who understand aspects of an individual's culture facilitates the building of rapport which is a useful tool for empowering people with mental health conditions, even if they are not from an identical ethnic or cultural background. In this way, it is recommended that people from black and minority ethnic communities have access to a culturally knowledgeable and diverse workforce that has an understanding of core benefits as

well as the main challenges faced by members of particular communities. This could also be supplemented by a digital database or resource bank of black and minority ethnic specialist organisations and services from across the VCSE sector that people can be signposted to as necessary, as mentioned in the preceding literature review.

In line with the reflections on heritage which was shown to be very important for some of the participants, and having the space to express how their heritage has influenced them and their ways of living, it would be beneficial to provide opportunities and platforms for this to be explored in further detail (perhaps combining it with music, photography or another art form) may be a useful way of demonstrating recognition and awareness of how culture influences mental health.

Furthermore, ensuring that staff are more open to discussing culture and cultural awareness will enable people to feel better understood and possibly more valued as individuals. Furthermore, as culture is important to mental health and wellbeing, PHBs should also cover activities coordinated or delivered by black and minority ethnic groups/organisations in the community.

Access to appropriate food and Lifestyle

When asked about keeping healthy, the influence of food choices and fitness habits on maintaining a healthy lifestyle was acknowledged by all participants. References were made to specific ethnic cuisines by two of the participants who also commented that they found certain foods from their culture as unhealthy.

B is well aware of the health implications that can be caused by eating an unbalanced diet and expressed her concerns about consuming certain foods that are staples in Jamaican cuisine which includes meat and starchy foods. Though she has cut down on these food types, she would like to use her PHB to pay for vegetarian cuisine that reflects her cultural & nutritional preferences.

M spoke about how she has had challenges with her teeth and the effect of snacking on biscuits. She has used her PHB to pay for cooking utensils and often watches teleshopping channels early in the morning in order to find more items to buy so that she can cook dishes that she likes at home. She expressed her excitement at being able to shop from home and buy things that she likes.

W has had problems with his weight for a number of years and is still struggling to manage his health. Using his PHB to pay for weekly Jiu-jitsu classes is both something he has wanted to do for a long time and something he feels will enable him to be healthier and help him to keep fit and lose weight. He is very happy that his PHB has facilitated these classes as it has allowed him to try out something new and assess its impact on his mental health before committing fully.

[Int] Do you eat a lot of Jamaican food?

[B] "Mmm not really. I do sometimes but I try to cut down on my weight, so I cut down on the Jamaican food. I would like the ackee and the saltfish and the yam the banana, but they make you put on weight… probably once in a while. There's a place in Great Barr we normally go. I normally go with my carer."

[Int] So if you could have access to a Caribbean shop that sold you, you know, good quality vegetarian meals, what difference would that make to you?

[B] It would help me a lot, cos it would help my weight a lot and I would be happy if I could find one. If I could find my one, and they do delivery, or I could make my way down there in a taxi and collect it and come back, I'd be very glad.

[M] Now that I'm older I realise I have been eating very well and healthy stuff. And my teeth are still in and I've lost a lot down the bottom and it makes me realise back to them and you've lost all your teeth on your bottom but you still have to get them crisps and wolf them down, you still managed to crunch them biscuits down. You've been alright so...

[M] I like to get up in the morning and what half an hour of the news on the BBC then I like to watch half an hour of the news on the ITV because I like to see how the BBC and ITV are working what they're presenting to people. If I get up too early I watch like to watch what they're selling to the audience of the comedy and turnover channels because they sell them things like, which I need which they sell on television which comes straight to your door which I can't carry since I've been having operations. Sauté pans which are made for electric cookers you can stack them and cook things really dry and cook with lots of oil or a little bit of oil vegetarian or vegan and if you wanted one of those and you went to know I don't know boots or John Lewis or Co-Op or Sainsbury's to buy these things they'd cost a lot more money because to pick up so when I see it on television, and I'm by myself I go "Oh my gosh, there it is is!" and so I just kind of go look on my phone, look at my purse, yes, the money's in there and I just (mimes paying for an item) "I've got it, I've got it!" I'm excited about my shopping and I never used to be excited about my shopping before.

[W] (describing why he chose to start Jiu-jitsu) …They say that all fights end up on the floor and once you're on the floor, that is it. So, they've got like hand locks and stuff like that so ummm, it's not just that, there's no punching, it's all self-defence and it's a philosophy of life as well so you live that life, so that's pretty much it…cos I've got the problem with the weight and everything else and not everybody that I know, people that work can't afford it you know….[Jiu-jitsu] That's £110 a month I mean, most gymships are like 20, 30, £50.

[Int] So has it allowed you to do things that maybe before you couldn't do?

[W] Yeah.

Due to each of the participants speaking about healthy eating and/or fitness and how the impact of weight management and physical health affects their mental health, it could be concluded that being able to use a PHB to gain access to a wider range of flexible options for unique fitness opportunities may be an area that has not yet

received much attention. There was also talk about access to food that is both healthy/nutritious and culturally specific which one of the participants found to be quite challenging. Nutrition is not just an important component of physical health, but also carries cultural meaning and can enable individuals to stay connected to their roots and communities. It is worthwhile to consider novel, unique functions of the PHB that can be rolled out to improve the outcomes of people from black and minority ethnic backgrounds further. An example of this could be to fund opportunities, whether via NHS dieticians or through the VCSE sector, to communicate advice and guidance on healthy meals and dietary advice that is specific to international cultures. This will allow budget-holders to enjoy food from within their community, whilst retaining the confidence that they are maintaining a healthy balanced lifestyle.

PHBs should also cover nutrition/food activities coordinated or delivered by black and minority ethnic groups/organisations in the community. Since, the experience and/or fear of weight gain and poor physical health meant that all participants took specific steps to utilise their PHB to improve their options and lead a more healthy lifestyle, considering the key aspirations of each individual and grouping them into categories may help commissioners to understand which provisions are missing from available provisions, as the existing range does not always address the nutritional/weight management needs of each person.

Religion and Belief

The topic of conversation turned to the theme of religion and beliefs as personal experiences were brought up by participants when discussing multiple factors that they believed had the capacity to influence their mental health. All participants specifically mentioned church as being important and acknowledged it as a notable form of support not just for themselves, but also for the people around them.

B spoke on how she sometimes speaks to God when she feels like she is suffering as she does not feel that she can talk to anyone else except a member of her church congregation. She also explained why she enjoyed church but linked this back to her difficulty with travel expenses as she requires someone to drive her to and from church, particularly if she is attending with her mother.

M described how her culture, religion and lifestyle are all different and that sometimes, other people may not understand this. She is happy that her PHB allows her to purchase things related to her religion and beliefs that do not require her to seek input from other people.

W talked about how emotional he felt after hearing that his brother had attended church in Portugal after not having been in a very long time. He expressed how much of a monumental step this was for him as his brother had lost his arm in an accident a few years ago and had also had difficulty with substance abuse which had impacted his brother's mental health and his own.

[Int] When you want to get out of the house, what kind of places do you like to go to?

[B] I like to go to Church even though I find it boring sometimes but just to get out and just to hear…, sometimes, because of my brain is not working properly, I normally go to church and they normally sing and they normally read the Bible and sometimes they preach and I find it very hard to concentrate on what they're saying my mind is on other things like keeping up with my shopping and making sure I've got enough things on my shopping list.

[Int] Normally, when you feel like you need help, who do you ask or who do you talk to?

[B] I suffer… I suffer. Sometimes, um, there's a church sister who I normally talk to but, not all the time. Sometimes I just suffer. Sometimes I just say to God help me. Give me strength.

[B] Sometimes I take the taxi, 'cos sometimes me and my mum goes and she will come for me in the taxi and we'll put together and then we go to church but sometimes we can't get a life back from church then we take the taxi together.

[Int] How is that for you, going to church with your Mum? How does that make you feel?

[B] It's good, sometimes when my Mum can't go then I go on my own and I like the company yeah…I like the company.

[Int] What would you say is very positive about having a personal health budget? Are there anything in particular that you think it's quite helpful having a personal health budget for?

[M] Um, being able to say no no no no no no no, my family don't know about this, no no no no no my brother's don't know about this, no no no no no my sister, that's not her idea, no no, that is solely my idea, I bought this because I like it. Because it reminds me of somebody because the Star of David is religious to me it's part of my lifestyle.

[W] My struggle with mental health, I had an episode back in 2014 and the previous one was 2012 so I went 4 years without having one then I came to London and they stopped my medication and said "you're fine" so you don't need to take any medication. Then my brother lost his arm in an accident and yeah and then that just kicked the mental health problem again so, so just you know, and now my brother's, cos he was using drugs, he's stopped using drugs now, so he's changed. Just a Sunday ago, he went to church and I cried, I hadn't cried for like 2 years even though I was in love and I didn't cry, when the break up happened, but um…yeah so being close with my brother, being physically there at least more than once a year would help me.

Each of these quotes serve to underline key findings from previous research with people from black and minority ethnic communities which has found that religion is often utilised both as a coping mechanism and a form of support that is viewed as distinct from statutory mental health provision that is not always understood by health care professionals (Rabiee and Smith, 2014). When discussing their religious and personal beliefs, no direct links to mental health were made, only to feelings which then impacted their emotional and behavioural responses.

Understanding the significance of religion and beliefs, and how this impacts on both mental health and day-to-day living is of the utmost importance, as this may also provide insight into opportunities for integration of the budget into religious activities and engagement within the community that can contribute positively to wellbeing and potentially act as a buffer to subsequent mental health issues. As such, PHBs should link to and/or provide options for access to activities coordinated or delivered by black and minority ethnic faith groups/organisations in the community as this will allow for a broader, more personalised approach to addressing the intersection between religion, belief and mental health. As this process relies heavily on local brokerage provided community and faith groups, it is critical for commissioners to consider how to develop their PHB offer, alongside how existing intiaitves such as social prescribing can be built into the PHB model.

Music and Photography

We asked participants about what they enjoyed in their spare time; if there were any activities, both generally and any that they felt related to their ethnic or cultural background, that they really enjoyed and felt that their PHB could be used for. For all participants, music was considered an important aspect of leisure, not only as a means of mental engagement, but also seen by some as a coping mechanism and a skill that could be shared with others. Photography was also mentioned by one participant as serving the same purpose.

B spoke about how she identifies with Jamaican culture. Though she spoke mainly about the cuisine she also mentioned reggae and gospel music, arguably the two most highly regarded genres in Jamaica, and how she engaged with music whilst living in Birmingham.

M described her history of learning to play an instrument and how this has led to her desire to learn a new instrument as an adult. She also believes that playing an instrument is a good skill to pass on to others and has been trying to encourage her daughter to try lessons.

W suggested that a good addition to the scope of the PHB would be to include things that people from young, black backgrounds could identify with in order to help them from getting involved in negative things or struggling to express themselves and/or articulate their experiences.

[Int] What are your favourite parts of Caribbean or jamaican culture? Do you have any things that you really really like?

[B] I like listening to music, but I've been to music for years now, so I get tired of it now, so I've got all my music and when I do put them on once in a while, it's just the same old songs.

[Int] What kind of music do you like to listen to?

[B] I like to listen to listen to gospel music and um, I like a bit of reggae… I play it on a CD or a cassette.

[M] I don't have the language to go forward sometimes in being able to execute my hobbies. I can only participate in photography on a hobby kind of way.

[Int] Is that something you are interested in?

[M] Yeah, it's my passion… If I can't afford, I just take something else away and then I put it back but then my sisters and brothers and family say "you shouldn't be doing that, you should be saving every penny you have you save it, you save it, you save it! And I keep telling them, "But I need a camera, or I need a recorder." Then they go "Yes but you're not a professional photographer or anymore, you've been very ill, why can't you get it into your head? Just relax." But I can't relax. I'm 57 I just feel I must have things I ought to be getting on with and friends I can keep up with and friends I can share things with. Sometimes, I really wanted something as a child and I managed to get it as an adult which I did, should I tell you what it is?

[Int] Yes please.

[M] I bought a flute! I always wanted to buy a flute when I was a little girl, but my parents said "we can't afford it" so I said "Ok Mummy, Ok Daddy" then they said "What about a clarinet? That's a bit more within our price range" and I said, "Ok Mummy" and they bought me one and I got into the orchestra with it, they took me on trips to Wales every year. I wasn't getting paid or anything, just very good experiences… At the moment I have to look after my daughter and I want her to learn from my mistakes too, not just only learn from my positives. I do get carried away with my photography and shopping money goes on it.

[Int] Looking at the list on the app, do you think it covers enough diverse things that people from Black backgrounds or Minority Ethnic Backgrounds would want? What do you think?

[W] Hmm… that's a good question. That's touched my buttons, yeah (laughs). Ummm I think… 'Cos being Black, like the culture, so when I was younger, I was more into rap and stuff like that, so I know that we're more into the street culture so maybe stuff like studio time and stuff like that. I'm not into that but yeah… You've got a lot of good guys who are good MCs they could rap about that about their core truths and what's going on and stuff like that. I think it would be good.

Two of the participants highlighted music specifically when asked about ethnicity and culture, with one participant reflecting on how music had been a part of her life since

her childhood and had caused her to use her PHB to purchase an instrument that she had wanted for several years. The impact of utilising mediums such as visual and auditory arts to support mental health has a significant basis in the literature however, less attention has been given to how this specifically impacts people from black and minority ethnic groups. The perspectives shared by each of the participants demonstrates the significance of utilising funding in the form of their PHB to develop creative skills and how this is meaningful in terms of mental health recovery, cultural expression and the potential for passing skills onto others.

Music was something that all three participants mentioned as a potential skill and/or coping mechanism both for themselves and for other people that they knew. It was evident that engaging with music in some capacity was of significant value and viewed as more than a mere hobby. As such, it would be useful to ensure that creative activities are well catered for in the PHB budget scope, as well as reviewing the options available at regular intervals so that items on offer can be updated or new options can be introduced. The significance of providing a creative platform for people to express themselves has been well reiterated here, and this is something that PHB providers should aim to facilitate.

Conclusions

The first of its kind, this report has evaluated both objective and subjective evidence relating to the implementation of Section 117 personal health budgets for mental health which were launched in December 2019. The knowledge gained from the review of literature was strengthened by the invaluable insight gained from one-to-one interviews which centred upon the lived experience of individuals from black and minority ethnic communities. These insights facilitated the identification of provisional strengths, as well as some shortcomings, which enabled the drawing of conclusions and emphasize what has worked well in addressing the health inequalities experienced by the people interviewed from black and minority ethnic backgrounds.

The findings of this study were largely limited by the sample size. This was due to a number of factors including delays to local and national roll-out of PHBs in certain areas, confounded by recruitment of people from black and minority ethnic communities who met the criteria for inclusion and due to the exceptional nature of the Covid19 restrictions. Additionally, participants did not reflect a broad range of black and minority ethnic groups, with all participants originating from a Black African or Black Caribbean background.

Nevertheless, the evidence from the interviews demonstrated that there are reports of positive experiences of PHBs by people from black and minority ethnic communities. All three participants welcomed the introduction of a PHB and were happy with the option of personalising their care as it provided them with a greater level of choice and control, which is more likely to improve personal experience and subsequently outcomes whilst addressing mental health inequalities. It is highly evident that this novel approach to care and support makes day-to-day living easier and more enjoyable through the reduction of burden and facilitation of independence in a number of ways. Participants' experiences of having a PHB have also meant that they have been able to try new activities and adapt aspects of their lifestyle that have previously been potentially problematic so that it is better suited to their mental health needs, consequently improving their perspective on their quality of life.

However, this review also found that improvement is still required across a number of areas. These are:

1. All participants expressed a desire to engage with their culture more often and/or more profoundly as a means of enhancing their mental health, although this was not that is supported by the available to them. This finding echoes findings from the literature that a significant cause of racial disparities in mental health is a lack of appropriate provision. This can be addressed by ensuring a system is in place for speaking to budget-holders about what they would find useful and ensuring that commissioners are kept informed and relevant provision is developed. The range of provision must also be considered, as budget-holders utilise their PHB to purchase both services and equipment.
2. Providing access to easy-to-understand materials that clarify the PHB process and systems, acknowledging the culturally-mediated influence of family life and responsibilities, as well having a diverse workforce who are relatable were critical elements raised by the participants which have reproduced key challenges and which have been present within the literature for several years. Recognising the relationship between lack of information and reduced agency/disempowerment is critical when seeking to engage people from black and minority ethnic groups.
3. It is important to employ people from a wide range of ethnic and cultural groups, as some people from black and minority ethnic backgrounds have expressed a desire to engage with staff from a similar background to themselves, largely due to an increased level of cultural understanding and rapport that has a self-reported positive impact on mental health. Increased diversity within the workforce will also serve to broaden the scope of PHB offer if suggestions from black and minority ethnic staff regarding the suitability and range of provision are incorporated as standard practice.

General recommendations

Many of the barriers to mental health engagement raised by the participants in this study can be addressed through the use of regular scoping exercises and reviews of services. This will allow people from a wide range of backgrounds to contribute ideas and feedback on specific types of treatments, equipment and activities that they would find useful, this will improve the diversity and overall capacity for

personalisation within PHBs. The need for this has been evidenced throughout the literature, with many people from black and minority ethnic groups reporting feeling disempowered by mental health services and the staff within these services due to a lack of cultural understanding (see Memon et al., 2016).

A broader range of options may also make PHBs more cost-effective, as evidence has demonstrated that targeted interventions are better value for money than general ones. PHB review appointments should include time designated to working with individuals in order to identify what their expectations for their budget are, and how these can be met and managed on an ongoing basis to prevent disappointment and disengagement.

Specific recommendations for people from black and minority ethnic groups

The right to have a PHB for people who are s117 eligible provides an opportunity by which the subjective social, cultural and spiritual experiences and beliefs of people from black and minority ethnic communities can be explored and understood by key professionals in the mental health sector, in partnership with people who want a PHB. Moving forward, commissioners and practitioners would benefit from revisiting the recommendations in light of the evidence presented in this report with their staff teams. This should be done in order to ensure that all relevant staff possess adequate knowledge and skills to effectively engage with and better implement PHBs for black and minority ethnic people in receipt of s117 aftercare. This will reinforce a commitment to the practice of ongoing learning that is rooted in the experience of people from black and minority ethnic groups who are in receipt of a s117 PHB as has been demonstrated by this report.

Additionally, written information in the form of a leaflet and/or details of an online website with clear, step-by-step guidance on what to expect from a PHB should be made available. Ensuring that budget-holders know the budget amount, payment dates, and examples of things that it can cover are also necessary to prevent ‘grey areas’ in knowledge and support transparency as all 3 participants were unsure about the details of their PHB. This will prevent power imbalances between service users and providers that are known to be a cause of disengagement from mental health services among black and minority ethnic people (Memon, 2016).

In line with the aforementioned recommendations, mental health care has reached a point where critical modernisation is not merely necessary but imminently expected. It is therefore advised that CCGs adopt these changes on both a local and national level, as it is imperative that this opportunity is not neglected.

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