

A review of Personal Health Budgets for people
from Black and minority ethnic communities

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Executive summary

Key action points for Commissioners of Mental Health Services

1. Include Voluntary, Community and Social Enterprise (VCSE) sector organisations within Integrated Care Partnerships (ICPs) as joint partners/collaborative providers.
2. Listen to Black, Asian and minority ethnic service users and ensuring that co-production is used every step of the way.
3. Be more visible in and more representative of the communities.
4. Create and support forums that allows representation from different organisations and encourage public and service user engagement and feedback.
5. Focus on regularly auditing needs and procuring services from within the community to meet them. Using more, smaller, tailored organisations as opposed to one large, less effective organisation will save money in the long term.

Key recommendations

When PHBs worked well, **people from Black, Asian and minority ethnic (BAME) groups with lived experience of using one** told us this was because they...

Listen to the needs and preferences of people with lived experience

BAME people told us that skilled and experienced professionals, particularly those working in primary care services are best placed to undertake regular check-ins with budget holders. This goes hand-in-hand with demonstrating accountability by co-producing feedback mechanisms with those who are experts by experience.

Additionally, they felt that by communicating how suggestions have been incorporated into practice (e.g. You said, We did), this reduced the likelihood of budget-holders feeling excluded and unheard.

Ensure the focus of PHBs is centered on individual needs and goals

The people we spoke to made it clear that by prioritising and facilitating ongoing dialogue, it will be possible to further empower individuals to develop skills for self-advocacy and become champions of their own care.

An effective foundation for any and all form of mental health support is well-rooted in the recovery aspirations of the individual and not their mental health symptoms or diagnoses.

Implement PHBs as a part of a holistic package of support

Evidence has shown that both medical and non-medical interventions work well for supporting people with severe and enduring mental illness. Likewise, our participants with lived experience also felt that PHBs work best when they are offered alongside medication, as many people rely on both in order to manage their mental health effectively.

When **Commissioners of mental health services in various parts of the UK** had built rapport and successfully engaged with people from Black, Asian and minority ethnic groups told us this was because they...

Make holistic personalised care the standard and anti-discriminatory practice the default

The positive experiences shared by PHB holders from BAME backgrounds across the country have set a standard for a new wave of personalised healthcare approaches in mental health. In listening to what matters to communities and to people, a number of commissioners nationally have shown how they have been successful in establishing invaluable working-relationships with groups that have been labelled 'hard-to-reach'.

Prioritise staff development and overall service efficacy

By ensuring that all staff involved in the commissioning and delivery of mental health services and personalised care have up-to-date knowledge and training of PHBs and personal empowerment, budget holders experiences' of their PHB can be improved. There is also scope for more effective use of existing online platforms and personalised care networks that provide opportunities for shared learning and staff support both locally and nationally.

Build on practices established during the pandemic

Many good examples of how staff and services responded to the unprecedented halt in face-to-face support exist yet are not widely publicized. Providing budget-holders with a range of online support options and developing tools for easy feedback are some of the triumphs that should be explored further across future assessments of PHBs.

Based on their experiences, **VCSE-sector staff with experience of working with people from Black, Asian and minority ethnic groups** suggested that Commissioners of mental health services could improve PHBs for them by...

Identify key and emerging communities and community groups within their CCG remit and invest in a PHB/personalised care communication strategy

Consistent data collection and effective utilisation will enable commissioners to better assess demand and target services more effectively. Most CCGs already have the resources to gather information on ethnicity (ethnic group, religion and language) within their local area however, more qualitative data that can translate numbers into profiles of need is required. Focusing on improving communication is the only effective approach to preventing exclusion of BAME groups through misinformation.

Utilise positive action to make space for underrepresented VCSE-led organisations

Making concentrated efforts to build relationship and collaborate with VCSE organisations that have knowledge and connections with people in the local community. This is particularly necessary for those organisations and groups that are BAME-led and often excluded from commissioning opportunities that have the skills and capacity to enhance existing NHS services through their collaboration and input.

Encourage service proposals and collaboration from community groups

Extending open invitations and calls to collaborate to local VCSE-sector organisations has been shown to facilitate dialogue at community level, which is imperative if local services (both statutory and voluntary) are to survive and thrive. This method of collaborative working can also highlight key elements of community mental health frameworks that commissioners may be unaware of or unable to access as a result of mistrust from historically marginalised groups.

In summary, the findings of this report strongly recommend that Commissioners of mental health services Reflect, Remember and Respond to the needs of people from BAME communities in the following ways:

Reflect

- When done well, PHBs have been shown to be a life-changing support option that makes a significant contribution to Black, Asian and minority ethnic people's ability to manage their wellbeing.
- A key strength of PHBs is offering a greater sense of agency and a heightened focus on the positive relationship between an individual's lived experience, their needs and their wellbeing.
- Good PHBs empower people to use to manage their care to the best of their ability, but also to challenge the support options that are available to them if they are not content with what is offered.

Remember;

- It is important to consider intersectional factors when supporting people who are stepping down from inpatient to community mental health services.
- There should not be any stress about goals, but a clear focus on recovery. It is important that the individual, and not their diagnosis, is at the forefront.
- Many people from BAME communities may have experienced racism, discrimination or have been let down by services previously.

Respond;

- Create clear, concise and consistent communication that is widely-available in a range of languages and formats. COVID-19 lockdown has demonstrated how powerful digital resources can be.
- Engage with regional and national Personalised Care networks and staff networks to reflect on best practice and enhance provision.
- Develop a network of key contacts within the local community and empower them to learn how to effectively engage with the commissioning process; Collaboration benefits everyone.

Introduction

Phase 1 – Expanding the Horizons of the s117 Personal Health Budget for Mental Health

Overview

The vision to make personalised care ‘business as usual’ for 2.5 million people by 2024, and 5 million people by 2028/29 was outlined in the NHS Long Term Plan (NHS England, 2019a). This shift in healthcare delivery encompassed a range of updates including improvements to the Personal Health Budget (PHB), which has become an automatic ‘Right to have’ for people who are eligible for Section 117 aftercare.

In January 2020, the Race Equality Foundation, in collaboration with NSUN and NHS England and NHS Improvement started Phase 1 of a project where we spoke to a small group of people from Black African/Caribbean backgrounds who have PHBs. The key themes from these discussions were in line with and provided context for factors perpetuating health inequalities and these were presented along with evidence from existing literature in a report entitled *‘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’* which was published in April 2020.

Background

A formal literature and evidence review at the time of the Phase 1 report demonstrated a considerable focus on ‘personal budgets’ rather than personal health budgets to date. This review also yielded a number of conclusive findings. Firstly, people from Black, Asian and Minority Ethnic (BAME) backgrounds are likely to experience poorer mental health outcomes and disproportionately detained under the Mental Health Act (Cabinet Office, 2018; DHSC, 2019). Secondly, there is a complex and under-researched interaction between elements of structural racism and a systemic misunderstanding and disregard of racial and cultural practices that sometimes leads to a distrust of formal mental health services among people from Black, Asian and minority ethnic backgrounds (Vahdaninia et al., 2020).

Additionally, both limited choices for true personalisation of care (both cultural and otherwise) and a persistent lack of appropriate communication regarding support options are a source of frustration for many people. It also 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. Furthermore, an analysis of PHBs by service users and carers revealed that there is a strong desire for access to more local, culturally appropriate services among people from black and minority ethnic groups (NHS Confederation, 2011). Finally, primary and secondary mental health services across the UK are experiencing an increase in demand for services. Consequently, any

Voluntary, Community and Social Enterprise (VCSE) sector organisations also serve as fundamental mental health care support points despite lacking in funding and resources.

Literature has suggested that an evidence-based way to address this challenge is to work in close partnership with organisations within the non-statutory sector. Many VCSE organisations have shown a continued capacity to thrive in their empowerment of black and minority ethnic people by providing ongoing support for the management of their needs. Evidence has also shown that community-level support is particularly effective when people from black and minority ethnic backgrounds are in leadership positions and focus on delivering support at local and regional levels (Butt et al., 2015). These findings have been supplemented by literature which has highlighted the importance of acknowledging and effectively mobilising the VCSE sector as a key contributor to wellbeing, health and care (Bignall et al., 2020).

Phase 1 findings

1-1 interviews were conducted with a small group of PHB-holders from BAME backgrounds across London and Birmingham. Following a thematic analysis of the 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

This report surmised that a critical focus for healthcare commissioners moving forward would be to invest in the provision of robust systems of support for enhancing mental wellbeing for the entire population. More specifically, by incorporating the multiple facets of a person's ethnic and cultural background as standard, facilitating a much-needed reduction in the health inequalities that reproduce racial disparities that are consistently observed in mental health care and outcomes for individuals from black and minority ethnic groups.

Furthermore, the findings of the lived experience interviews reiterated conclusions made in existing literature concerning also suggested that it would be useful for practitioners to instigate discussions pertaining to people's cultural needs, due to the novelty of PHBs and limited understanding of how they can be used. In order to present options for truly bespoke personalised mental health care, the onus remains on CCGs 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. Likewise, clear and consistent communication of information relating to how PHBs can be used was highlighted as a mechanism for reducing 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).

The key recommendations of the Phase 1 report were for CCGs 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.

Secondly, it was advised for practitioners and commissioners to make concentrated efforts to engage VCSE sector organisations to expand the scope of PHB provision by ensuring 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.

Additionally, it would be beneficial 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.

Finally, PHBs can 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.

Phase 2 – A Comprehensive Review of s117 Personal Health Budget for Mental Health

i) Lived experience interviews

Overview

In order to directly build on the findings from Phase 1, a similar, slightly more brief question guide for semi-structured interviews was created. The main focus of the Phase 2 interviews was to address the comments and suggestions made during the previous phase and compare the views of different people with lived experience of similar services in different geographic locations. A selection of quotes that encapsulate the fundamental ideas shared are highlighted in ***bold italic***.

The lockdown restrictions meant that face-to-face conversation in a familiar place was not an available option, despite this being the preference of most lived experience participants. During each of the discussions, the impact of Covid-19 on mental health and daily living were highlighted. This was, without exception, initiated by the participants themselves and largely related to feelings of being trapped, isolated/alone and not being able to attend certain events and venues that had become a regular feature in their recovery and wellbeing journey.

Summary of themes

A number of key themes and subthemes emerged from the lived experience discussions. These were:

1. Focus on me and not my mental health

- a) How clinical and non-clinical support both help me
- b) More than just money

2. How to improve my experiences of personalised care

- a) Understand my culture and my needs
- b) Diversify your PHB offer

3. Responding to Covid-19

- a) How I managed my mental health during a pandemic

What works well

Based on these findings, we were able to conclude that commissioners and service providers would benefit from acting to:

- *Listen to the needs and preferences of people with lived experience*

Professionals, particularly those working in primary care services are best placed to undertake regular check-ins with budget holders. This goes hand-in-hand with demonstrating accountability by co-producing feedback mechanisms with those who are experts by experience and communicating how suggestions have been incorporated into practice to reduce the potential for exclusion and act on them to reduce health inequalities.

- *Ensure the focus of PHBs is centered on individual needs and goals*
An effective foundation for any and all form of mental health support is well-rooted in the recovery aspirations of the individual and not their mental health symptoms or diagnoses. By prioritising and facilitating ongoing dialogue, it will be possible to further empower individuals to develop skills for self-advocacy and become champions of their own care.
- *Implement PHBs as a part of a holistic package of support*
Evidence has shown that both medical and non-medical interventions work well for supporting people with severe and enduring mental illness. Our participants with lived experience also felt that PHBs worked best when they are offered alongside to medication, as many people rely on both in order to manage their mental health effectively.

Findings

1a: How clinical and non-clinical support both help me

The opening discussion question “Can you tell me about yourself and your mental health?” sought to understand how participants described their mental health experiences in relation to their everyday lives and in their own words. There was a clear consensus among the participants’ accounts that emphasized a key Phase 1 finding; the key to improving PHBs for all is to focus on the individual as a person, rather than placing their mental health need(s) and diagnosis at the centre of their recovery journey.

“I feel like I wouldn’t even have mental health issues if from the very beginning I was treated like a person and not just someone who people don’t wanna be around.” [BA]

“The people that treat me, they don’t really know me. They just know my file. But the people at [my local] Mind, they know the real me” [MT]

“With the right support, I know I can get better. My support workers are my main help, but I don’t want to put everything on them. I need to be able to do it by myself. I want to be able to do it by myself.” [SA]

Due to its role as the primary treatment option for severe and enduring mental illness, participants spoke openly about their views on drugs/medication (both prescribed and non-prescribed) and the impact they believed this to exert on their lives.

“Meds work but they’re just a plaster. The cut underneath can be exposed at any time and sometimes plasters fall off by themselves” [BA]

“The workers, they keep my money. They don't let me have it and annoys me... (Pauses) at the same time I guess it's a good thing because when I've got my money I just spend it all on cannabis 'cos that's what makes me feel better about myself and my life. I take the drugs they give me, and it helps a bit but not much” [DN]

“I got diagnosed with schizophrenia when I was 15 and I'm 40 now. I don't really feel like medication is effective for me. I don't think that medication... it's not that effective for me anyway. If I tell them I'm ill, they'll put me back on Clozapine and Clozapine is the thing that makes me feel really really bad.” [MT]

Although medication has an ongoing role in several participants' lives', their views on medication as an isolated treatment form were mostly negative or indifferent. This further reinforces existing knowledge on the importance of developing holistic treatment packages that address individuals needs across a variety of domains.

Additionally, people mostly spoke about themselves and their mental health in relation to the people and organisations around them. Echoing the insights shared in Phase 1, the role of non-statutory staff support in providing a sense of stability, accountability and encouragement was repeatedly highlighted. This often led to a discussion on how participants actively chose to manage their mental health through the use of both medication and non-medical, sometimes socially-prescribed remedies, with the latter being often being used as a standalone treatment.

“Sometimes you just need someone to talk to who ain't gonna judge you for who you are. That's why a lot of people have problems with their mental health, because people are actively stopping them from tryna be themselves.” [BA]

“I found out about a local organisation through my son. He plays football with some lads and it's one of the lads' Dads who runs it. It's good to have someone to talk to who understands you and doesn't judge you.” [HN]

“I've been through trauma; sometimes I don't want to talk to a professional. I really like going to church. That helps me. I've got friends there, but it's closed now because of the lockdown.” [SA]

The role of VCSE-sector organisations in providing person-centered care was acknowledged with great positivity. The greatest strength of these organisations being cited as their capacity to provide support and acceptance without judgement.

The underlying desire to become and/or remain independent (i.e. not requiring significant involvement from statutory/inpatient services) was also mentioned however, in order to ensure this goal is achieved, it is clear that a stronger link between appropriate resources and services offered by the different sectors must be made available and attainable to all consistently.

1b: More than just money

As the topic of conversation turned to how PHBs and mental health support are funded and what this means for people who were in receipt of supportive payments, it became clear that parallels between this topic and the phase 1 theme of “Scope of the budget” could be drawn. This led to emergence of a second subtheme, which focused on how the money is spent and the perceived impact of this on subjective mental health.

A number of people mentioned using money received either via a PHB or from benefits (e.g. Personal Independence Payments received from adult social care services) to fund social activities. The key concept being that this budget facilitated engagement with services in the community that have the capacity to improve mental health and wellbeing, even if this was not their primary aim. Receiving a budget removes the barrier of financial exclusion, a fundamental factor in social exclusion and subsequently isolation.

“I pay £5 to go to pepper pots where they give you a hot meal. Sometimes rice and peas, sometimes oxtail and they make the veg. It's nice 'cos you get to spend time with people from different backgrounds and places. But we're missing out now cause of lockdown, so everything is online.” [SA]

“I don't really have much money to do stuff. I think if I had more money then I would be able to get out more and have more of a life” [NI]

“My PHB has given me the chance to do things that I wouldn't have bothered to do otherwise. Cos when you're getting your benefit, you're thinking about surviving, you're thinking about how you're gonna get to the next payment. You're not thinking about going to the gym or buying products for yourself to better yourself.” [BA]

Evidently, being afforded greater freedom to leave the house and attend a regular, structured event that was not directly focused on mental health was very important for the wellbeing being of certain participants. This increased level of liberty was a direct result of having access to a PHB and the main reason why many people continued to engage with services.

Additionally, the benefits of taking part in activities and having things to do to stay occupied was highlighted by several participants. There was a clear relationship between being mentally stimulated/engaged and feeling able to manage one's mental health and wellbeing. The deterioration of mental health and increase in negative symptoms was attributed to a number of factors. Of these, boredom was the most commonly mentioned.

"It helps with the symptoms if I'm busy." [MT]

"When I'm bored, it makes my mental health symptoms get worse." [DN]

*"At home, there's nothing to do except think. Sometimes when I can't sleep, I have to call the Samaritans because I hear voices. Sometimes it's good, sometimes it's bad."
[SA]*

Participants' accounts clearly demonstrated the usefulness of having a PHB, particularly with regards to enabling them access to specific activities which served as outlets and distractions that were beneficial for helping them to manage certain negative symptoms. The non-prescriptive nature of the PHB not only allows individuals to decide which interventions and resources are right for them, but also offers a niche advantage that has a significant capacity to empower people to regain a sense of agency over their mental health journey.

2a: Understanding culture

Building on from phase 1, participants contributed an abundance of insights on how their experiences of culture and personal cultural needs were related to their mental health experiences. Unlike the previous discussion points which related to more general PHB improvements that are applicable to budget holders from all cultural backgrounds, this dialogue focused specifically and exclusively on the impact of aspects of culture on mental health and wellbeing from the perspective of people from black and minority ethnic groups. When asked what their culture and background meant to them and if/how this impacts their experiences of mental health, participants shared a range of detailed reflections.

"Some staff don't think about culture...it's pretty generic really. Mental health professionals don't really understand culture. It would be good if they knew but they usually refer me to somewhere. I don't really hold it against them" [MT]

"Growing up as a mixed-race child with a white mother in a white area meant that I didn't really think about my black side. I just knew I wasn't fully white and that was it. Looking back, my mum didn't really know how to look after me, like my hair and skin and stuff and it affected me so badly. I learned about my culture 'cos I taught myself as an adult. So, you need representation from all parts of a person's identity to make a whole." [BA]

"I don't have to keep explaining Bangladeshi culture to him. He knows because it's his culture as well. If I had to keep re-explaining things, it would really tick me off. Cos you just think, 'this is such a waste of time talking about certain foods or my family values

and what not'. I'm past that. I want to talk about a recovery plan now. My culture is something you should just know at that point." [HN]

"I like to rap. I love music because it's a big part of what people do where I'm from. I'm only telling you that 'cos you're black and you're from Tottenham so you'll understand. My white support worker is a white lady. Bless her, she's lovely, but if I spat my bars for her, she'd think I was mad. She'd be like 'what on earth are you saying?' I just wanna be understood 'cos it helps me." [DN]

During each of the conversations, the topics highlighted as being of specific cultural value were identical to the themes drawn from the Phase 1 Lived Experience interviews. In particular, religion, music and food preferences/dietary habits re-emerged as fundamental elements that were indicative of each individual's identity and what was important to them and their mental health journey. Ultimately, it was made clear that participants did not feel that their culture, in and of itself, were directly responsible for limiting their PHB and mental health experiences, but rather a perceived lack of initiative in effectively incorporating knowledge and understanding of culture into mental health service provision.

2b: Diversify your PHB offer

Further to the key recommendations proposed in the 'Expanding the Horizons' report, a solution proposed to further enhance PHBs has been to consider improving their scope through the inclusion of a wider range of options which are eligible to be covered by the budget. In the current phase, this was encapsulated within the theme 'diversifying the PHB offer'. Within these discussions, specific attention was given to the tangible steps that could be taken to ensure PHBs are utilised more effectively. In turn, this will enable PHBs to address the challenges relating to holistic cultural representation that present a persistent challenge to traditional mental health services.

"I don't think they would be able to do something for every ethnicity. It would be too much. And some people come from more than one or two countries. They would just need to do what works for each individual person." [NI]

"They don't really encourage you to go places owned by Asian people. But if you ask, I think they would say yes." [MT]

"I don't like some foods, so the food is important. Even at my church they do different foods and people come from different countries. It's important that everyone feels like they're equal. It's not nice if you get left out. It would be good to have stuff to do like a sewing machine or Christian books. I use my phone for the art therapy because my computer is really slow, it doesn't work. But I can't afford new stuff." [SA]

The significance of certain cultural and religious practices/routines were identified as a key influence on the management of day-to-day living for the vast majority of participants. A number of people interviewed across both Phase 1 and 2 shared that they believed their PHB had an untapped potential to provide them with access to culturally-specific events and resources that would benefit their mental health. however, when attending meetings with

the professionals involved in coordinating their PHBs (i.e. PHB advisors), this possibility was not raised by staff or budget-holders. This suggests that there is great unspoken potential with regards to how staff both advocate for and communicate the dynamic and truly personal nature of a PHB.

3a: Covid-19: Rapid Mental health management in a pandemic

In March 2020, the announcement of a nationwide lockdown led to isolation at levels never seen before. Activities and services that many people relied on heavily for social interaction and motivation to leave the house were shut down completely, instantaneously, and indefinitely. Despite many organisations' response to the national restrictions, it took a while for online alternatives to get going and even when they did, not all were accessible or appropriate for peoples' needs. As restrictions appeared to relax, the continued uncertainty concerning when and how things would 'return to normal' created a new challenge for the statutory and voluntary sectors and the people that utilise their services. Navigating the COVID-19 pandemic has been difficult for a variety of reasons for many people whose family are not always living locally; this has led to a significant increase in feelings of isolation and separation that were further exacerbated by the need for social distancing and reduced travel whilst in lockdown. Keep in touch with family via social media as they do not live close.

"Football is a good distraction. It lets me get fit and I speak to people. I can't do that anymore cos we're locked up inside. Music is helpful for most people but makes my symptoms go worse. So, when people say if you're lonely, listen to music. I can't even do that". [MT]

"I spend a lot of time by myself. I like it cos I have to like it. It's not nice if people don't want to spend time with me. I live in a flat and we can't meet up anymore" [NI]

Adjusting to only being able to communicate via technology was a challenge expressed by most participants. For some, using digital applications was a useful tool for engaging with others during lockdown whereas for others, its role as a potential trigger for negative mental health was a focal point.

"I do art therapy every 3 weeks. We have to do it online through Zoom cos of the lockdown. I get really lonely so it's good and it's nice to see everybody on the screen. It's not the same but what can you do. It's better than having nothing." [SA]

"Sometimes when people ring me, I don't pick up. And my support worker gets annoyed and stuff like that. I used to think that I was being tracked and followed so I didn't use my phone. People told me I was paranoid. I still don't really like using them, but I don't want people to worry about me more than they have to so I do what I can really." [NI]

"Yeah everything's online now. You can't even go anywhere. They moved my support group online... Can't go gym... I don't really mind it you know, I kinda just had to get

*on with it. I can stay at home and see people. It was a bit weird but it's alright now.”
[DN]*

“Well you can only really use technology if you know how to or if you have someone in your house to help you. I have my son, he studied computers at uni, so he knows how to do everything. If I get stuck, he'll help me. I know how to use Zoom a bit now... I didn't get any outside help.” [HN]

Undertaking the digital switch proved challenging so many people across the country. Yet for some people with severe and enduring mental illness this proved to be even more difficult. Managing loneliness and isolation during the pandemic, particularly without the support infrastructure that they have become used to, forced most people to depend on strength and willpower in a way that is different to what they are used to.

Lived Experience Summary

The perspectives shared during the interviews demonstrated a significant degree of overlap between participants' lived experiences from both Phase 1 and Phase 2. For many people, having a PHB has been a liberating experience that has provided a fresh outlook on the ongoing self-management of mental health and wellbeing. Being able to focus on enjoying activities of daily living independently and feeling better (reducing negative symptoms). A number of people shared that they felt that negative mental health symptoms worsened as a result of boredom. Consequently, having access to a PHB that facilitated regular hobbies, as well as support with employment and training opportunities (e.g. Recovery college, setting up an online business, completing GCSE/access qualifications).

PHBs provide access to support options that many people find incredibly beneficial. For individuals experiencing severe and enduring mental illness who did not have access to a PHB, when describing a package of support that would best meet their needs, a concept identical to a PHB was the most proposed option.

Having a PHB also provides increased financial flexibility to engage with structured activities. This engagement, in turn, appears to have the potential to both increase positive and reduce negative mental health symptoms. This finding emerged in the discussions with both PHB holders and people who did not have a PHB. Whether used as a distraction from symptoms, a way to cure boredom or as means to achieve goals in other areas of life, access to a PHB grants people a broader choice of options with regards to positively impacting and managing support options to support their general wellbeing.

ii) National Webinars for NHS Commissioning staff

Overview

We conducted a total of five webinars that were attended by a total of 64 people. Each webinar was facilitated by the team at the Race Equality Foundation (*Jabeer Butt, Esther Ayoola and George Bell*), lead staff from NHSE/I (*Janet Blair and Charlene Onofiok*) and PHB Programme Lead for the City and Hackney colleague *Breda Spillane*. The first two webinars also included a pre-recorded welcome video from *James Sanderson*, the Director of Personalised Care at NHS England and Improvement. In three of the webinars, short talks were given by speakers from regional-based, BME-led organisations (*Bristol Somali Resource Centre, Lancashire BME Network and Legacy WM*) and we were also joined by lived-experience speakers, *Harun and Bex*, in two of the webinars.

The primary aim of this webinar series was to apply the knowledge acquired from Phase 1 to equip commissioners with an enhanced knowledge and understanding of addressing health inequalities through the implementation of PHBs. Each webinar started with a quick introduction to PHBs and the potential benefits they provide, followed by an outline of the findings from phase 1 of the project.

As each webinar followed an identical structure, similar topics arose during the discussion. Key themes included understanding and promoting ethnic diversity and representation, mutual expectation management, increasing collaborative-working with VCSE sector organisations, particularly those with experience working with and networks among black, Asian and minority ethnic communities.

During the discussion sections, important conversations that produced useful suggestions and key questions regarding the implementation of PHBs, such as the critical need for more guidance and training on conducting cultural needs assessments, were raised. The value of forming working relationships with VCSE sector organisations was also mentioned, due to the clear value of these organisations to enhance the planning and implementation of personalised care. Some attendees also brought up the importance of staff diversity, such as seeing more people who are representative of different cultural backgrounds. Additionally, the importance of providing adequate support to people receiving PHBs so they understand the options available to them to help achieve their recovery goal was also discussed; as well the need for race and culture to be given more consideration. A key strength of this webinar series was bringing a range of health and social care experts from across entire regions together, who were able to contribute suggestions for potential improvements to PHBs for people from black, Asian and minority ethnic communities.

The success stories being shared by different people both those with lived experience and NHS commissioning staff about the positivity and hope brought by PHBs and personalised care. One lived experience expert who was also a PHB-holder praised the extra control it gave her compared to other mental health services she had used and liked the fact that it made her feel more human. An example was given of one individual using their budget for an African clothes-making course which provided them with skills, a routine and a group to be involved with. From the discussions, it was made clear that whilst there is undeniably still

more room for improvement, PHBs have provided many people with the opportunity to negotiate care that is reflective of their identity and recovery goals. When implemented correctly, the scope for impact is potentially life-changing. The success stories and feelings of positivity shared throughout this webinar series was useful for identifying the challenges but also serving as a catalyst for change and progress in the roll-out of PHBs across the country.

iii) Discussions with senior NHS Commissioning staff

Overview

We carried out 5 one-to-one interviews with commissioners of mental health services. This included one commissioner from each of the regions as outlined in the webinars. A selection of quotes that encapsulate the fundamental ideas shared are highlighted in ***bold italic***.

We asked each of the commissioners the same set of predesigned questions which were based on the VCSE sector interviews and focus groups and the lived experience interviews and that focused on:

- Potential challenges of targeted focus on PHBs for people from BAME communities
- Examples of best practice
- Key commissioning priorities
- Cultural competence and cultural assessment
- Expanding and upskilling their workforce

Summary of themes

1. **Focusing on the individual**

a) The meaning of person-centred care: Tailor-making the 'right' PHB offer

2. **How we plan to improve personalised care and PHBs**

a) Knowledge and training for our workforce

b) Peer learning and accountability

3. **Learning from Covid-19**

a) What the pandemic taught us

4. **Ideas for collaborative working**

a) Working with the VCSE sector

b) Who benefits when we collaborate and learn from BAME-led VCSE organisations?

What works well

Based on these findings, we were able to conclude that *commissioners are best placed to commit to revising all aspects of the commissioning process in order to:*

- *Make holistic personalised care the standard*

The positive experiences shared by PHB holders from BAME backgrounds across the country have set a standard for a new wave of personalised healthcare approaches in mental health. In making this the norm, it may be possible to shift negative perceptions of historically excluded communities to formal mental health services.

- *Prioritising staff development and overall service efficacy*

By ensuring that all staff involved in the commissioning and delivery of mental health services and personalised care have up-to-date knowledge and training of PHBs and personal empowerment, budget holders experiences' of their PHB can be improved. There is also scope for more effective use of existing online platforms and personalised care networks that provide opportunities for shared learning and staff support both locally and nationally.

- *Making anti-discriminatory practice the default*

In listening to what matters to communities and to people, a number of commissioners across the country have been successful in establishing working-relationships with groups that have been labelled 'hard-to-reach'. A key learning is that working to dismantle the systems and procedures that present a barrier to engagement to people from BAME backgrounds is both essential and constantly required.

- *Building on practices established during the pandemic*

Many good examples of how staff and services responded to the unprecedented halt in face-to-face support exist yet are not widely publicized. Providing budget-holders with a range of online support options and developing tools for easy feedback are some of the triumphs that should be explored further across future assessments of PHBs.

Findings

1a: Knowledge and training for the NHS workforce

Interviews with commissioners opened with a brief overview of themselves and their role, their current remit and the history of mental health and personalised care within their region. The focus of the discussion centred on 'the key challenges faced by people from BAME groups engaging with mental health services in the local area' and 'practices that have been or will be put in place to address these challenges'. As anticipated, responses varied between regions however, there were a greater number of similarities in experience and perspective than points of difference.

For the first main theme 'how we plan to improve personalised care and PHBs', a central concept was captured by views on the current workforce and how this could be enhanced. Similarly, to the lived experience and VCSE-sector interviews, the importance of knowledge and understanding both the needs of local community groups and the true personalisation of care were stressed.

“The Mental Health Act pretty much opposes true personalised care. It affects different people from different communities differently. And being culturally aware is really important. We have a very big travelling community in [our region] and sometimes mental health staff can use jargon which is overwhelming and puts people off.” [AG]

“We need diverse teams and a diversity staff population who are open to learning and improving accessibility.” [EE]

“We need to know the numbers of BAME people in order to focus our work better. It is important to understand the needs of each minority group that is represented in the population.” [ES]

“A mandatory session for staff discussing inequalities was really helpful to air some of the views people had. We need to get rid of the attitude that PHBs are extra work.” [TW]

Overall, a key factor that commissioners wanted to highlight was the view of CCGs as consistently developing and striving to do the best for all. It was consistently made clear that although the current workforce is highly skilled and represents a wide range of people with diverse knowledge, there is always room for improvement and development at both local and national levels. Repeated use of the term ‘we’ demonstrated a positive outlook on collective responsibility and acknowledgement of how systems can sometimes operate to exclude or further marginalise people from certain groups.

1b: Peer learning and accountability

In addition to a recognised need for gaining knowledge and insight on the needs of people from local Black, Asian and minority ethnic groups from members of the communities themselves, a parallel requirement to commit to peer learning and accountability within CCGs was also identified. Each commissioner shared one or more examples of how they had sought to tackle this challenge and why they believed it to be important.

“People sharing their stories in person with commissioners is what we need more of. Some CCG board members and college students attended a talk where a patient shared her story of what led her to try and end her life. It was just so powerful... After that piece of work, she done, she'd gone round to schools and became a speaker.” [EE]

“It is important to be clear about the specific funding that is available for addressing inequality because we are very good at collecting lots of data, but people are thinking ‘what the hell are you doing with the data? How are we making sure that these inequalities are addressed?’ and they are right. We owe it to them to be transparent and to let ourselves be held to account.” [ES]

“There needs to be an equality lead who can keep track of an area and hold people to account for it.” [SN]

“We’ve introduced a call each week where voluntary sector, service providers etcetera can talk about these things. This has allowed issues to be addressed in a fast way. It’s far reaching, and a diverse range of views are represented.” [TW]

The significance of clear and consistent communication of progress and intent came across as a fundamental element of what commissioners viewed an effective mental health provider to do. These views addressed some of the concerns shared during the VCSE-sector interviews, during which a lack of transparency and accountability to members of the community and to non-statutory, particularly BAME-led organisations were highlighted. This also echoed points made during the regional commissioning webinars calling for more intentional and wider advertising of safe peer learning spaces similar to the ongoing Communities of Practice, in addition to more opportunities to learn about relevant work that is being undertaken regionally.

2a: The true meaning of person-centred care

During the interviews, commissioners also spoke about their views of person-centred care that lies at the heart of PHBs. This largely stemmed from reflections on conversations that had been had with PHB-holders, as well as critical questions that had arisen from strategy meetings and reviews of how well CCGs had been doing with regards to meeting targets that had been set based on local needs (feedback from people using their services) and national standards (e.g. NHS Long Term Plan and NHS: People Plan for 2020/2021).

“People have said things like ‘It is about understanding and respecting my culture not necessarily reflecting it’ and ‘I am not defined by my mental disorder, but you keep assessing me as though I am’. I’ve learned that the focus should be on four key things; (1) My life (2) What’s important to me (3) What I’m scared of and (4) What I’d like to achieve. Then the professionals’ perspective has to be signed off by the person with mental health difficulties. In doing so, the sense of accountability becomes a mutual exchange between the clinician and the individual utilising the service. As mentioned previously, accountability is a key element of sustained empowerment.” [AG]

“Different types of needs should be accounted for - make it easier for everyone across the board. People with complex needs require a much more targeted intervention.” [ES]

“We really concentrate on a person-centred discussion. We need to consider, what more could be done to support the families around the individual, as well as the individuals themselves?” [SN]

“Continuity of care is important – should have the same consultant wherever you are on the recovery pathway. We need to look at what is important to the individual,

which also puts some responsibility on them and must consider the needs of carers involved in the planning and discussion as well.” [TW]

In line with the recommendations from the Phase 1 report and alongside the views shared during the phase 2 lived experience and VCSE-sector interviews, the consensus among commissioners to focus on the individual as opposed to a set of guidelines and procedures was made quite clear. There was a strong emphasis on the different methods and practical ways that could be used to ensure that the individual remained at the centre of their offer of a ‘person-centred’ PHB.

Furthermore, when considering the association between culture and PHBs, some commissioners shared that based on their experiences, many needs of PHB-holders were in fact universal needs and not distinct to any particular cultural or ethnic group. Notwithstanding, there was an acceptance of the fact that care should not be called personalised, nor a PHB be called personal, without adequate recognition of a person’s culture and the potential impact of aspects of that culture and the way others perceive it, on a person’s mental health. Although sometimes there was some tension whether something was a cultural or social need or not, the general attitude was to accept it as valid, so long as their benefits to mental health and wellbeing could be established.

“Sometimes you reflect, and you think, this is not a cultural need, it’s just a need that we cannot support and need outside help to. It’s not bad to admit that. We are fortunate here because staff are not afraid to say, ‘we don’t know what this means’. Some people are excluded due to boundaries that are set by the government or by systems...” [AG]

“There haven’t been specific discussions about approving culturally significant items. I think it’s generally assumed that people will have their requests accepted as long as they are considered important for recovery... There was this old Jamaican man, who wanted to get some clothes rails for his uniforms. He’d been in the forces and his uniforms were a significant part of his background. He’d been out and served this country and before he got his PHB, his uniforms were just sitting in boxes in his flat. That was all he wanted, just rails for his uniforms. Literally just rails. Being able to look at them when he felt down was a major boost to his mental health and sometimes, yes, it’s just that simple.” [TW]

3a: Learning from the Covid-19 pandemic

Similarly, to the lived experience and VCSE-sector interviews, the impact of Covid-19 was further highlighted by commissioners. From their perspectives, there were a number of pre-Covid19 difficulties that were exacerbated by the pandemic; these difficulties also meant that there were now several key learnings that should be drawn from what has happened.

“For certain people, lack of access and accessibility served as a significant barrier, even prior to the pandemic. “People’s feelings around restrictions and isolation were not good during Covid-19, simple things like producing information in all the correct

languages were missed. Covid-19 shone a light on this. Things need re-examining so they can be improved.” [TW]

“Look at what’s happening around us. We have a lot to learn about how we deal with crises. If anything, Covid has taught those of us who take good mental health for granted what it’s like to actually be in a state of crisis. We shouldn’t have to be affected by something personally before we take action to make it better.” [SN]

“I can’t think of anything worse than a lockdown for someone who has a mental illness. It’s hard for everyone but being physically isolated indefinitely...[pauses] I just, it’s just so hard for people. Cracks really started to show, it really was a learning curve. We won’t forget it.” [AG]

“It has been kinda good in that certain things that could have been done online before are fully online now. It forced us to be more resourceful than we were and also to not take things for granted. Zoom has really helped us and Microsoft Teams... Lockdown tried but we tried harder!” [EE]

Though it is difficult to quantify the extent to which the coronavirus pandemic disrupted existing healthcare systems and practices during 2020, it is also indisputable that some much-needed change occurred as practitioners and commissioners rose to the challenge. In certain parts of the country, digital PHB packages including items such as smartphones, sim cards and laptops were promptly implemented as means of guaranteeing that hundreds of people could remain connected with their support network. The abrupt ceasing of face-to-face support and introduction of an indefinite period of lockdown led to a substantial delay in the planned rollout of PHBs in many regions. In summary, although the pandemic presented an unprecedented and significant burden to CCGs delivery of mental health services, it also provided an opportunity for an immediate re-evaluation of provision and priorities.

4a: Working with the VCSE sector

When asked about what changes they felt could be made to the way services in their remit are commissioned in order to better meet the needs of people from BAME communities, all commissioners mentioned improved links with VCSE-sector organisations as being an important priority moving forward. This was because the non-statutory sector was seen as a critical vehicle for learning and ultimately improving engagement.

“There have been times where if I can be honest, it seemed as though senior management were resistant to change... Risk averse commissioning is not helpful. Proof and stories should be enough to change things and we’ve seen so many examples of where this has worked so well with the voluntary sector. Building a catalogue of proof will help us try to stay away from simply data gathering.” [AG]

“I think the biggest advantage of starting small when working with the third sector, is that you can make it bigger. If you try to start big and it doesn't work, you will need to scrap it rather than downscale, which is not good. I think the best advice I could give is

to write up a business case about who your local partners are and work with them. Stick to it. Make the right contacts and things honestly just go from there.” [ES]

“We don't always have good representation. I found that visiting assets in the local community... actually taking myself down there and talking to people, that's what's worked well in the past, but this idea hasn't always been well received by all the staff in the CCG.” [EE]

Some staff had felt that although there were approaches they had adopted previously or felt would be beneficial in enhancing people from Black, Asian and minority ethnic communities experiences' of PHBs, they had encountered differences of opinions with some of their commissioner colleagues who did not share their views. Overcoming this challenge presents an additional obstacle for a number of commissioning staff, particularly when dissonance between the preferences and feedback of PHB-holders and frontline staff and the responses of CCGs.

4b: Who benefits when CCGs collaborate with and learn from BAME-led VCSE organisations?

Additionally, some commissioners felt that there were distinct advantages to working with BAME-led VCSE sector organisations or developing BAME targeted services to address the needs of particular groups represented within their local communities. For example, in one CCG, a new helpline was set up and was viewed as having been successful as there had been talk about people from Black, Asian and minority ethnic backgrounds accessing this service at higher rates than they were accessing traditional face-to-face services however, the ethnic breakdown of people using this service is still unknown. This is a key challenge for many services across the country and an element that will need to improve to ensure that initiatives are being utilised and targeted effectively.

“There is a lack of trust from various minority ethnic communities around what mental health problems are and how they are addressed. If it came from someone who knew the community and was a part of it, it would make things a lot easier for all of us. There are several grassroots organisations whose knowledge and expertise could be better utilised but do not receive much funding. We are looking at developing a primary care in-reach thing and wanna look at how the voluntary sector plays a key role in that.” [TW]

*“As a society, we don't like seeing pain. We mask that pain with medication, and this does not align with how other countries and cultures view mental health and illness. There are small groups in distant counties that meet certain ethnic or cultural needs there is also a large Muslim community in parts of our region some of the stuff we offer is not culturally appropriate, but **we are trying.**” [AG]*

“We need to know the numbers of BME people can you use what is already there as a platform. Ringfenced funding for addressing inequalities is that, it's there. But what the hell are you doing with the data? How are we making sure that these inequalities

are addressed? We are trying, but there is a lot to be done. We need to simplify the process because sometimes systems and protocols can make it more difficult.” [ES]

“Since updates have been made to our online counselling services, we have noticed an increase in referrals of people from BAME backgrounds. We have also started changing how we monitor ethnicity. I feel that being from a BAME background shouldn't be a barrier, but during our CAMHS transformation we didn't have many BAME parents.

*Having multilingual parenting practitioners, particularly from Asian backgrounds, has made a massive difference. **We can now rely on word of mouth to promote our services. When we engaged members of the traveller community, they respected the opportunity to co-produce posters even though many of them couldn't read...**We've done more work in schools, particularly in the Asian schools where they have been great at supporting the EMHPs and CAMHS. We've also done work visiting traveller sites and mosques which has worked well in the past, but this idea has not always been well received by some members of the CCG.” [EE]*

“I think some commissioners can be hesitant at times to work with BAME charities or community organisations because it can make them look like they don't know what's going on but we can't really progress unless we accept that no one person knows everything and perhaps we are best placed to help communities to help themselves.” [SN]

On the whole, commissioners were very much open to sharing key learning and reflections they had gained throughout their time working across personalised care and mental health. There appeared to be a positive acknowledgement of a wide range of needs that affected the experiences of people from Black, Asian and minority ethnic communities across all the regions and a thorough understanding of what could be done to address the challenges they faced. Whilst it is important to have a service that all have equal access to, it is just as important to ensure that the service caters fairly to all. In order to do this, it is indeed a collective responsibility within CCGs to ensure all services advertised as 'personalised' or 'person-centred' have been designed to readily adapt to draw in knowledge and facilitate change when required. Thus, it is ultimately down to PHB teams to advocate and communicate feedback from PHB-holders to staff within the CCG who are responsible for making decisions at a strategic level.

Commissioner summary

There are numerous national examples of the positive impact of PHBs and how they serve to increase people's sense of agency, reduce their need for hospitalisation and high-intensity clinical interventions as well as to help them to better manage their negative mental health symptoms. When considered holistically, it is these factors that contribute to the prevention of relapse and readmission to inpatient services and ensure that the individual does not continue to regress, even during periods when opportunities for progress may appear limited.

The benefits of commissioning services that empower people are seen in the progress of individual journeys which are sometimes overlooked. CCGs would benefit from gathering feedback from PHB-holders on their experiences of utilising their budget. It is important to evaluate PHBs based on their demonstrable capacity to improve people's quality of life, rather than evaluating and comparing numbers without context.

As the rollout and refinement of PHBs continues, there is likely to be varying views on what is 'appropriate' and 'effective'. The commissioner interviews reaffirmed that in order to ensure the best outcomes, focusing on what works well for budget-holders is often the best option.

There is clear desire among commissioning staff across regions to engage with non-statutory services however, this has not historically been done. Moving forward, forging relationships and designing services where collaboration with VCSE-sector organisations and local community groups is standard must remain a top priority.

iv) The Voluntary, Community and Social Enterprise (VCSE) sector discussions

Overview

For this phase of the project, our focus was on exploring the key challenges to the effective implementation of personal health budgets for people from black Asian and minority ethnic backgrounds. The purpose of this was to identify potential solutions in the form of tangible action points that could be utilised to aid personalised care in mental health services nationally. A selection of quotes that encapsulate the fundamental ideas shared are highlighted in *bold italic*.

The staff and volunteers who attended came from a range of general and BAME-specific voluntary, community and social enterprise (VCSE) sector organisations. These individuals also represented a number of ethnic backgrounds.

Summary of themes

1. **The true role of the VCSE sector**
 - a) Our work, aims and practices
 - b) Knowledge and understanding of PHBs
 - c) Understanding the mental health of and empowering communities and individuals
2. **Racism, discrimination and our work**
 - a) BAME-led, VCSE sector organisations vs. the Commissioning process
3. **Responding to Covid-19**
 - a) Adapting our infrastructure and resources

What works well

Based on these findings, we concluded that both commissioners and frontline staff would can enhance PHBs by:

- *Identify key and emerging communities and community groups within their CCG remit*
Consistent data collection and effective utilisation will enable commissioners to better assess demand and target services more effectively. Most CCGs already have the resources to gather information on ethnic and cultural backgrounds within their local area however, more qualitative data that can translate numbers into profiles of need is required.
- *Utilise positive action to make space for underrepresented VCSE-led organisations*

Making concentrated efforts to build relationship and collaborate with VCSE organisations that have knowledge and connections with people in the local community. This is particularly necessary for those organisations and groups that are BAME-led and often excluded from commissioning opportunities that have the skills and capacity to enhance existing NHS services through their collaboration and input.

- *Encouraging service proposals from community groups*

Creating open invitations and calls to collaborate that are extended to local VCSE-sector organisations will facilitate dialogue at community level which is imperative if local services (both statutory and voluntary) are to survive and thrive. May highlight key constituents of community mental health frameworks that commissioners may be unaware of or unable to access.

- *Investing in a PHB/personalised care communication strategy*

Clear, concise and consistent communication is the only effective approach to preventing exclusion through misinformation. Acknowledging community languages, preferred communication styles and the significance of wording are elements that VCSE-sector staff viewed as simple yet also believed were the most common reason for lack of engagement.

Findings

1a: VCSE work, aims and practices

We asked participants about the work that their organisation was responsible for and what they felt the key aims and priorities of their work were. A number of people shared what they felt the ethos of their organisation was:

“The work of our organisation aims to get people from our community to really trust and engage with NHS services.” [DB]

“We work to address the understated need of supporting the mental health of people who are caring for relatives/friends. It’s quite hard to be responsible for someone else’s recovery.” [BL]

“If a service user has identified an interest, we build on that as a basis for development.” [FG1]

“We try to teach people in our community about mental health but it’s hard because there is no direct translation of this term in our language – only madness.” [AB]

“People come to us when they don’t know what to do and we never ever ever turn anyone away. We make sure that we find them the help that they need.” [TS]

The information shared demonstrated an array of direct work, linking and signposting that was taking place supplementary to or in some cases, prior to the intervention of statutory

service provision. The focus on relational working and the way each participant highlighted people and individuals when describing their function only attested to the person-centred nature of the work being done by their organisations.

There was also a highly evident focus on and dedication to understanding the needs, culture and ways of working of both individuals and communities. This commitment was frequently hailed as the cornerstone of service provision and motivation for staff and volunteers. The topics within this theme mapped directly onto Lived Experience theme 1a with regards to the desire for a consistently person-centred focus. The strong alignment of views from both VCSE-sector staff and people living with long-term mental health difficulties, both those who were PHB-holders and those who were not, only served to reiterate the importance of this approach as standard.

1b: Knowledge and understanding of PHBs

For many people, knowledge of PHBs and personalised mental health care were extremely limited. This was due to not having access to information and not having a consistent link into their local CCG. Ultimately, a lack of awareness of PHBs is likely to mean that people may be misunderstanding/missing out on what they may be entitled to.

“To my knowledge, there are no people within our community who are even aware of a personal health budget or this system.” [DB]

“I’ve never even heard of a personal health budget before today. If I don’t know what it is then [laughs] I just highly doubt that other people do.” [BL]

“People can only go to what they know. If they’ve never heard of something, then you can’t exactly expect them to engage with it... this is why I think the terms ‘hard to reach’ and ‘disengaged’ are really unfair.” [UP]

“It’s basically a secret service! Nobody even knows about it. What’s the point in it if nobody knows about it? How will people benefit from it? I would assume it’s probably a bit of a postcode lottery to be honest. If you live in the ‘right’ area, you usually get access to more stuff, better stuff.” [QT]

This notion related closely to findings from Phase 1, in which some PHB-holders reported not fully understanding the purpose and scope of a PHB despite having received one for quite some time. Although guidelines on the ‘Right to Have’ a PHB were published on the NHS England website available for public viewing in December 2019, the lack of clarity surrounding who PHBs are intended for and exactly what they can be used for is likely due to a lack of available literature and communication of clear and concise information concerning PHBs in locations that people from Black, Asian and minority ethnic communities are likely to access.

It is also noteworthy to mention that similarly to a small number of lived experience participants that were interviewed, several VCSE sector staff had never heard of a PHB until they took part in the project. This included a majority of staff who had been supporting

people from black, Asian and Minority ethnic communities experiencing severe and enduring mental health conditions for several years. This demonstrated a significant lack of awareness, due in part to the substantial delays in roll-out caused by the Covid-19 pandemic but also, as the commissioner interviews highlighted, as a result of unsuccessfully engaging people from black, Asian and minority ethnic backgrounds in statutory mental health service provision.

1c: Empowering communities and individuals

The Lived Experience interviews from both Phase 1 and 2 revealed a number of challenges related to agency and self-advocacy when engaging with formal services. Building on from a key recommendation to support PHB-holders in increasing their confidence in communicating with staff in statutory services, we asked VCSE staff what they believed the term ‘empowerment’ meant and how they went about including this in their day-to-day working:

“Personal empowerment is subjective. It means confidence... assurance in people and services to be better, to do better and to help them recover.” [YT]

“We try to put the power back in people’s hands because services can be very protective of people sometimes and this sometimes means that people cannot identify their own needs and interests.” [FG2]

“Some people are institutionalized and desperately want or need support and are reluctant to move on without the help of services. We empower these people to do what works best for them.” [AN]

“There’s too much variation in the level of where people are starting out once they’re discharged. I think proper personalisation takes a lot of time and learning and is ongoing.” [QT]

One participant also mentioned that when considering personal empowerment in terms of PHBs, practitioners and advisors asking ‘why’ and utilising lines of questioning that require people to give reasons for their thoughts and feelings can sometimes seem like rejection to some individuals. This is a key challenge as all items requested as a part of a PHB must be accompanied by further information indicating how their request contributes towards their recovery goal. For some individuals, this can create an additional sense of pressure, particularly if they have become used to a diminished sense of agency as a result of being hospitalised.

“I think it would be helpful to have a step prior to even being offered a PHB... when people are sectioned, they become used to not being in control which is not good. So suddenly saying “here you go, here’s your PHB for you to manage” can be quite daunting. Some people don’t even know what would benefit them ‘cos someone else has decided that for them for however long.” [YT]

Though it has significant potential to impact lives, there are also a number of considerations to be made when offering and supporting the coordination of a PHB. This is particularly true

for people who do not feel empowered to engage with services due to previous negative experiences of mental health support services. Ultimately, in order to ensure that PHBs are indeed personalised and that the experience of having a PHB is distinct from previous styles of mental health management that may have caused people to lose confidence in services. As such, it is extremely important to frame questions carefully, with a focus on addressing needs.

2a: Racism, discrimination, inequality and the VCSE-sector

A number of staff shared their concerns about how people's mental health is impacted and the risk of this continuing unaddressed. There was a significant focus on social challenges and what this meant in terms of intersectionality and mental health outcomes.

"Structural inequalities lead to poor mental health becoming somewhat contagious among certain minority communities, particularly as the burden of care and dealing with stigma falls onto family members." [DB]

"In certain boroughs, there is a lack of housing or the housing is very expensive like, it costs 75-95% of people's wages. How can you live like that? Stuff like that definitely causes people to spiral into problems that affect their mental health." [IP]

"Social issues have a very big or should I say the biggest impact on people's mental health. BAME people are more likely to have poverty and so more likely to experience mental health issues." [AB]

"Having a natural curiosity about culture and relatability and genuine investment in people is very important for reducing disengagement." [FG2]

There was also a keenness to highlight how a lack of consideration for people's language needs was contributing to people feeling left out and unable to access services. In this context, inequality was discussed as a contributing factor rather than an outcome.

"British sign language interpreters are mandatory, but this is not the case for sign language in other languages. Issues such as this arise and create challenges because there is no clear guidance. There is no clear guidance for budget-holders or NHS practitioners/VCSE sector staff with regards to the right to an interpreter." [YT]

"Continuity of care leaflets in different languages and formats will help to reduce disengagement and knowledge biases." [TB]

"People who are ESOL need examples to avoid confusion and back and forth which may cause them to hit a stumbling block that can lead to loss of confidence." [AL]

For some staff working at BAME-led VCSE sector organisations, they felt that there was a significant risk of being not very well-liked especially if they challenged commissioners/funders/NHS on matters relating to inequality, racism and funding. This, in turn, would subsequently have implications for future relationships/funding. Additionally, it was believed that different organisations were held to different standards depending on their history and relationship (favouritism).

“They’ve tried to silence us, they don’t want to hear us, they don’t want to give us a voice. They want you to question yourself and they hold us back.” [BL]

*“We’ve spent a lot of time trying to secure funding for user-led projects but it’s hard. **Sometimes it feels as though the commissioners don’t see our value even though everyone else does and there’s constant demand for our services.**” [TS]*

“The burden on our communities to help themselves is and has always been overwhelming to be honest. If we don’t help ourselves, I doubt anyone will help us. People see us as different; they think we’re rich.” [YB]

Historic negative experiences of commissioning or attempting to commission services in collaboration with a particular trust have led to some VCSE sector organisations losing faith in the commissioning process. This was particularly felt by some VCSE staff who had worked in their roles for many years and had witnessed several changes to leadership or service design and provision. Both overt and covert incidents of racism and/or discrimination were cited as key factors responsible for discouraging certain non-statutory organisations from reaching out to and developing partnerships with local statutory services.

Additionally, in our discussions with VCSE staff and volunteers, a number of significant factors that were strongly believed to impact on the health and wellbeing of people from Black, Asian and minority ethnic backgrounds were identified. Many of these are related to the delivery and in some cases, the absence of targeted services.

*“Ok, so we don’t like to talk about race but is everyone getting an equal chance to be empowered through the work that the staff in their CCG/local community are doing? **That’s the question.**” [YT]*

*“White people always have been and always will be the majority. We need more Black people, more Arab people, more mixed-race people working in the NHS, sure, but **what we really need is White professionals that genuinely understand the mental health of non-white people and how the challenges they face impact their mental health on a fundamental level.**”[NC]*

In spite of a large degree of overlap and in some cases what could be described as siloed or disconnected multi-agency support, There are many individuals receiving statutory support report being happy with their support package, the staff responsible for delivering these services have expressed discontent with the way in which organisations engage with one another and are eager to work towards positive change.

3a: Covid-19: Adapting non-statutory infrastructure and resources

For many VCSE sector organisations, continuing to work at the peak of the covid-19 pandemic was a necessity. Through their rapid response and utilisation of digital communications platforms, many VCSE sector organisations were able to continue working. However, this was not the case for all. Several organisations had no choice but to operate services at an extremely limited and uncertain capacity, with some being forced to close altogether. For those that were able to remain open, finding new ways of working and serving their communities became a matter of urgency as it became clear that long-term adaptations would be necessary.

“Covid has made things a lot harder to do over the phone. Many people who are most at risk and rely heavily on our services either don’t have access to the right tech consistently and/or don’t have the confidence to engage with it.” [FG1]

“We introduced a fast track pack on our website that outlines all the key features of the most common digital communication software that helps our clients to get going as quickly and as smoothly as possible.” [YT]

*“We carried out a technology audit of all service users and created a scheme of work that included a step-by-step guide on how to carry out common tasks such as how to download Zoom, send an email and whatnot to make sure that the information staff are giving clients is consistent, clear and concise. In fact, **we spent over £12,000 on PPE and deep cleaning our office building. We didn’t have the money, but we wouldn’t be able to stay open if we didn’t.**” [TS]*

“Well our socially distanced visits by caseworkers are still continuing, so long as they can be done in line with government guidelines, risk assessed etcetera. This is something that a lot of people really do appreciate because feeling lonely or isolated is what is impacting their mental health the most and visits are the only thing that can really negate this. Even if it’s just popping by for a quick chat and standing at the gate or dropping off a food parcel. Zoom is still very isolating and doesn’t feel ‘real’, especially for those who didn’t use technology for that purpose pre-lockdown, you know, like some of the older people.” [NC]

Despite this, a key challenge faced by many organisations related to funding and sustainability of services but also working to manage a complete reduction in their capacity for face-to-face service provision. Online platforms became the primary basis for interaction and service delivery with several organisations being forced to respond instantaneously. As media coverage during the peak of the pandemic continued to highlight the challenges faced by the NHS, it seemed that the work of many VCSE sector staff and volunteers became camouflaged.

*“People looked at us as just doing our bit... which we were, but it was much more than that. **The strength of our organisation is also its biggest weakness; people rely heavily on us in times of trouble and we have no choice but to deliver.**” [TS]*

*“Unsung heroes... that’s how I’d describe the charity sector. Full of people not getting the recognition they deserve. **People risked their lives in this pandemic. Not because it was their job, ‘cos many people out there were volunteering. To do that for free and not want anything in return... that’s humanity.**” [YB]*

Mirroring the statutory sector, the invaluable nature of the VCSE sector is often reinforced during a time of crisis, with several key learnings that have become evident as a result of the Covid-19 pandemic. For example, the resilience and perseverance of the VCSE sector to meet people at their point of need and offering a bespoke level of support that extended beyond its initial remit. In addition, the resourcefulness and willingness of many organisations to respond to an unprecedented with no clear end-date exerted a significant positive impact on the lives of many people that has been greatly appreciated and widely praised.

VCSE-sector summary

The VCSE sector holds immense value that would improve the mental health experiences of people from underrepresented ethnic groups: The links, relationships, trust, knowledge of different ethnic groups, community language skills among other things are aspects that the VCSE sector offers in abundance and that statutory services require in order to offer more personalised healthcare provision. Ultimately, the VCSE sector could potentially save the NHS/health economy money if it were to be utilised more effectively.

The interviews with VCSE-sector staff also complimented the vast majority of the findings from the lived experience interviews and aligned with most of the views shared by commissioners. Based on these findings, a number of questions were compiled that VCSE-sector staff felt could only be reflected on and answered by commissioners:

Key questions for Commissioners of mental health services to reflect on

The information gathered from the focus groups and interviews were utilised to generate the topic-guide for the commissioner webinars and interviews. Based on these findings, the key questions VCSE sector staff wanted commissioners to reflect on were:

- What communications are being sent out to people? Are these consistent locally and nationally? Should they be?
- Is the information that is being shared fit for purpose for the communities that you serve? Does it address their wants and needs as well as giving consideration to experiences of racism and disadvantage and how this affects people's mental health journeys?
- Targets and waiting times are also an issue. Having to work to these limits the level of personalisation that staff can offer clients. What will be done about this?
- When will CCGs be able to provide accurate, reflective, up to date data on minority communities? This is particularly important with regards to the impact of intersectionality on health inequalities affecting minority ethnic communities that is currently largely unaddressed.
- Should there be a step prior to even being offered or providing a PHB? Something that happens at the point of discharge or immediately prior to prepare people for what is coming next and how having a PHB will affect their recovery pathway.
- There is an ongoing debate concerning whether or not to provide examples of what the PHB can be used for as this could be seen as influencing people in their decision-making. Why is this debate still ongoing?
- Is everyone getting an equal chance to be empowered through the work that the staff in their CCG/local community are doing?
- Personal empowerment is subjective. It means confidence assurance in people and services to be better to do better and to help them recover. How can this be shown to be the rule and not the exception across all services at all levels?
- If we could ask our commissioners anything, the question for us still remains 'what are your priorities? Why is health inequality still so low down on your list?'

General summary

It is imperative to highlight that the findings demonstrate that when done well, PHBs can become a life-changing support option that makes a significant contribution to people being able to manage their wellbeing. They do this by offering a greater sense of agency and a heightened focus on the positive relationship between an individuals' lived experience and needs and their wellbeing. It is also apparent that lived experience is something VCSE sector organisations value immensely and requires a diverse approach, particularly with regards to the mental health of people from black, Asian and minority ethnic backgrounds. This is largely because people with severe and enduring mental illness have varied levels of access to PHBs. This is somewhat of a postcode lottery and is entirely dependent upon where an individual lives and what provisions their local CCG has in place to support people with severe and enduring mental illness in the community.

VCSE sector support tended to focus predominately on addressing social, cultural and spiritual needs that helped people to feel more equipped to manage their mental health. The PHB, though underpinned by money, has an impact in a range of domains beyond the financial. Through direct and indirect means, the holistic benefits of engaging with a PHB are distinct from other forms of intervention that have been offered previously. This is important to consider when supporting people who may be stepping down from inpatient to community mental health services. Collaboration and partnerships between VCSE sector organisations and NHS CCG partnerships are absolutely critical and have great capacity to improve the roll-out and ongoing implementation of PHBs. Based on the information shared by VCSE sector staff, volunteers, people with lived experience and commissioners, it is clear that focusing on goals and tools for improvement is likely to have a greater impact than focusing on budgeting. This means that the key underlying message should be that there should not be any stress about goals, but on recovery.

In order to improve mental health outcomes for people from black, Asian and minority ethnic backgrounds through the use of PHBs, it is first necessary to break down the barriers that prevent people from accessing the fundamental things that they need, such as education, employment and housing. Additionally, personal empowerment that gives people the confidence and skills to manage their care to the best of their ability but also to challenge the support options that are available to them if they are not happy should be a key priority. It may be helpful for some prospective budget-holders to have examples but need to follow up and make it clear that it is just an example.

It was consistently suggested that practitioners and staff can be very protective of people due to their concerns regarding inappropriate interventions and the effects of these on causing people's mental health and wellbeing to regress. This, in turn, can mean that people struggle to identify their own needs and interests. In spite of this, recovery is about stable change. Hence, consistent, non-pressured, well-informed interaction is significant for PHBs to be implemented successfully. All practitioners must remember to demonstrate unconditional positive regard to the people that they are working with. They are human and should be treated as such consistently. It is important to remember that people may have already been let down by services previously.

Additionally, many staff working in VCSE sector organisations are supporting people who may be eligible for PHBs yet were unaware that this initiative existed. CCGs should seek to develop a network of key contacts within the local community who can offer information, advice, and guidance for existing and upcoming initiatives and who can learn how to effectively engage with the commissioning process. Commissioners should also seek to reduce the impact of racism and discrimination in the commissioning process that excludes local organisations from initiating collaboration.

Ultimately, in working together, the VCSE sector and NHS should focus on an end goal of creating an inclusive system whereby nobody is turned away. There is a need for nationalisation, but also need personalisation it is all about balance. Peer learning on local and national levels can only serve to strengthen people's experiences of PHBs and personalised care.

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