

#### Community insights 2020-2023





#### **About this document**



The report provides a cross-thematic analysis of 6 listening exercises delivered between 2020 and 2023 in communities who are Black African and Caribbean, South Asian and living with poverty.

- 1. Black African and Caribbean (BAAC) Obesity Insights (2020, Public Health Lewisham)
- 2. BAAC Mental Health Insights (2021, South East London CCG)
- 3. Diabetes Outcomes that matter to people in BAAC and South Asian communities (2022, South East London ICB)
- 4. Heart Valve Disease/ TAVI awareness and acceptability in BAAC communities (2022, Guy's and St. Thomas' Trust)
- 5. Stop BP Hypertension study in racially minoritised / deprived communities (2022, One London)
- 6. Acceptability of Vital 5 Check in BAAC, South Asian / economically deprived communities (2023, King's Health Partners, South East London ICB)

We take an evidence-based approach to our work. The above exercises were based on the COM-B model for Behaviour Change (Michie et. al 2011) or the Theoretical Framework of Acceptability (Sekhon et. al 2017).

Click me to find out more about COM-B

<u>Click me to find out more about the</u> <u>Theoretical Framework of Acceptability</u>

### Where is the opportunity for change?

All our projects have the goal of amplifying 'seldom listened to' voices, to improve the design and delivery of health services and treatments. When we think about our findings, we find it useful to think about where the various themes or factors we hear sit within the wider system i.e. where is the opportunity for change? We think about these factors across the following three categories:

#### Individual and Community Factors

These factors are most directly linked to individuals themselves or the communities they identify with. For instance, where culture or faith has a role in how we think about how health or the way we think it should be managed.

#### Relationships with Healthcare Professionals and Local Health Services

These factors are most directly linked to the care people receive at a local level and the people who provide the care. For instance, how much dignity and autonomy people feel when speaking to clinicians, or the availability of appointments.

#### Impact of wider system and societal influences

These factors most directly link to the wider policies and process that influence the care people receive, for instance which health research or services are funded. It may also include the 'wider determinants of health' e.g. income or people's experiences of discrimination.

## Key themes across all studies

Across the studies included in this analysis, we highlight the following key themes, listed according to which category they most closely relate to. Further detail on each of these themes is described on the following pages.

Individual and Community Factors

- Health knowledge and awareness
- Individual beliefs and concerns
- Personal influences on behaviour change capabilities
- Friends, family and wider social circle's impact
- Community involvement in healthcare provision

Relationships with Healthcare Professionals and Local Health Services

- Beliefs and concerns about accessing services
- Beliefs and concerns about clinical approaches
- Interactions with individual healthcare professionals
- Racism in interactions with healthcare professionals

societal influences

Impact of wider system and

- Racism in healthcare
- Healthcare system's service offering
- Digitalisation of healthcare
- Data Sharing



## Summary of themes, community voices and recommendations



# Individual and Community Factors

What they can do is collaborate with us on projects. Yeah. Because there are things that they clearly can do. And there are things that are difficult for us to do... so we need help to promote our services. But we can reach people that the NHS struggle to reach. They call Black people hard to reach people, we reach them all the time. We can't not reach them, they're all around us.



### **Key Themes**





**Health knowledge and awareness:** Community members have a good level of general health awareness, but lack specific illness/ lifestyle change knowledge, nor do they know the resources available to help treat these conditions.



**Individual beliefs and concerns:** While in general, community members believe it is important to be an active agent of one's health, some disengage due to lack of confidence and beliefs about the health trajectory being fixed.



**Personal influences on behaviour change capabilities**: While community members are motivated to engage in health behaviour change, physical/mental (ill) health, family commitments and/or high cost or lack of resources can make lifestyle changes challenging.



**Impact of friends, family and wider culture:** While friends and family can play an important role in motivating a person to take care of their health, there is a strong impact of culture on lifestyle habits, and beliefs about health/ certain health issues.



**Community involvement in healthcare provision:** Individual community members and community organisations want to be involved in developing and delivering health services, but there has been a decrease in funding for community-based initiatives.

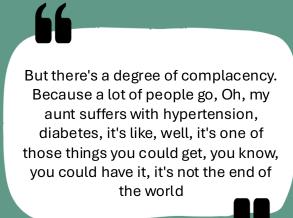
#### What we heard from participants

MAB Adi Liko



I don't want to be a person that relies on quick fixes, versus doing what might be hardwired in myself to be a good steward of my own body. So there's something there about personal responsibility and accountability that I think about

Your BMI is notoriously not a good indicator of health... in South Asian and Black communities, there needs to be a bit more sensitivity when it comes to talking about health and weight, and how to sort of handle that without being disrespectful or dismissive of the person and of their lived experience



Money resources very tight, and we tend to eat to fill our stomach. So people eat very heavy starch based food to fill their stomach

## **Key Recommendations**

- 1. Provide dedicated, condition-specific campaigns about prevalence, risks and care services (e.g. hypertension).
- 2. Create communication campaigns specifically focused on reinforcing health self-efficacy\* among minoritised groups.
- 3. Work with community groups to develop and offer implementable lifestyle change advice and support.
- 4. Run community outreach campaigns, working with community members to reinforce social norms regarding effective health engagement.
- 5. Organise and fund the community's involvement in the development of health interventions to ensure they are tailored, culturally appropriate, and address health inequality.

\* Self-efficacy is the belief that someone has the ability to act in a way that will help them achieve a specific goal. The term was coined by psychologist Albert Bandura in 1977.

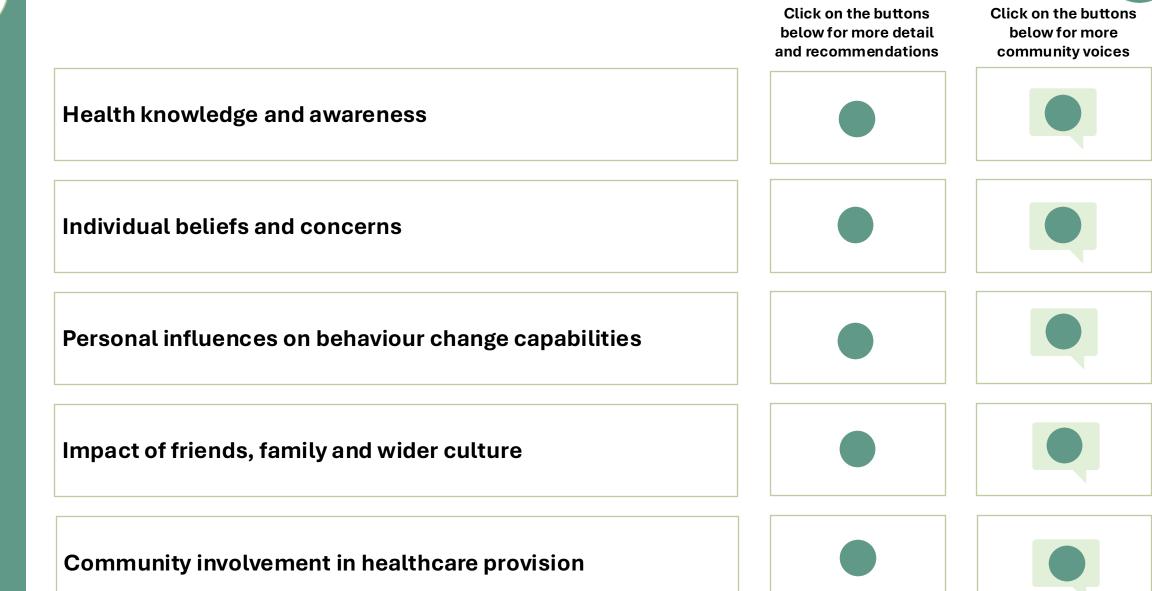




Individual and Community Factors

#### Find out more

MAB ADI LIKO





# Relationships with Healthcare Professionals and Local Health Services

[Some] will fight for you. Sometimes it's like they're on their own doing that, but they will fight for you for that particular thing for your health... so I think sometimes we've got to remember that they all come as individuals...with individual personalities. Some can be very arrogant, but some can really, really fight to want to help you. And I've experienced both sides."



Relationships with Healthcare Professionals and Local Health

Professionals and

ervices

Ś

## **Key Themes**





**Beliefs and concerns about accessing services:** While in general, community members believe it is important to be an active agent of one's health, some disengage due to distrust or fear derived from negative experiences, and the complexity of healthcare pathways.



Beliefs and concerns about clinical approaches: Community members have concerns about the overmedicalisation of health, and that treatments are predominantly designed for White Europeans. They also raised concerns around sharing negative feedback.



Interactions with individual healthcare professionals: Entrenched hierarchy of healthcare professionals over patients, and their communication style, mean that community members often feel that these professionals do not respect their values, culture and tradition.



**Racism in interactions with healthcare professionals:** Experiences of interpersonal racism and discrimination at the hands of healthcare professionals fuels distrust and avoidance of the health system and reduce community willingness to engage in any healthcare intervention.





## What we heard from participants



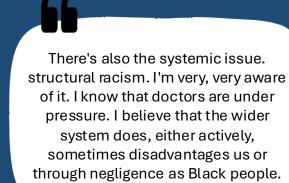
**Professionals and Local Health Relationships with Healthcar** ervices Ś



I also thought of the NHS pressure, they don't need to see me I don't need to waste their time, because, you know, they've got other more important things to do



You can tell a doctor who tells you what to do and the one that converses with you right? Someone who takes the time to explain things to you, who listens to you, you know, and takes into consideration your views



I used to be very compliant but I've

had multiple health issues. I've

become more inquisitive, finding out what it's good for me and I can

navigate better



## **Key Recommendations**

- 1. Create communication campaigns specifically focused on reinforcing health self-efficacy among minority groups.
- 2. Simplify and clarify healthcare pathways to ensure people are treated in an appropriate and timely manner and follow-ups are provided.
- 3. Provide training on cultural humility and empathic communication to HCPs.
- 4. Provide training on cultural sensitivity/ humility and the impact of systemic racism to HCPs to help them integrate ethnorelative (vs. ethnocentric) perspectives of ethnicity, religion and culture in patient engagement.





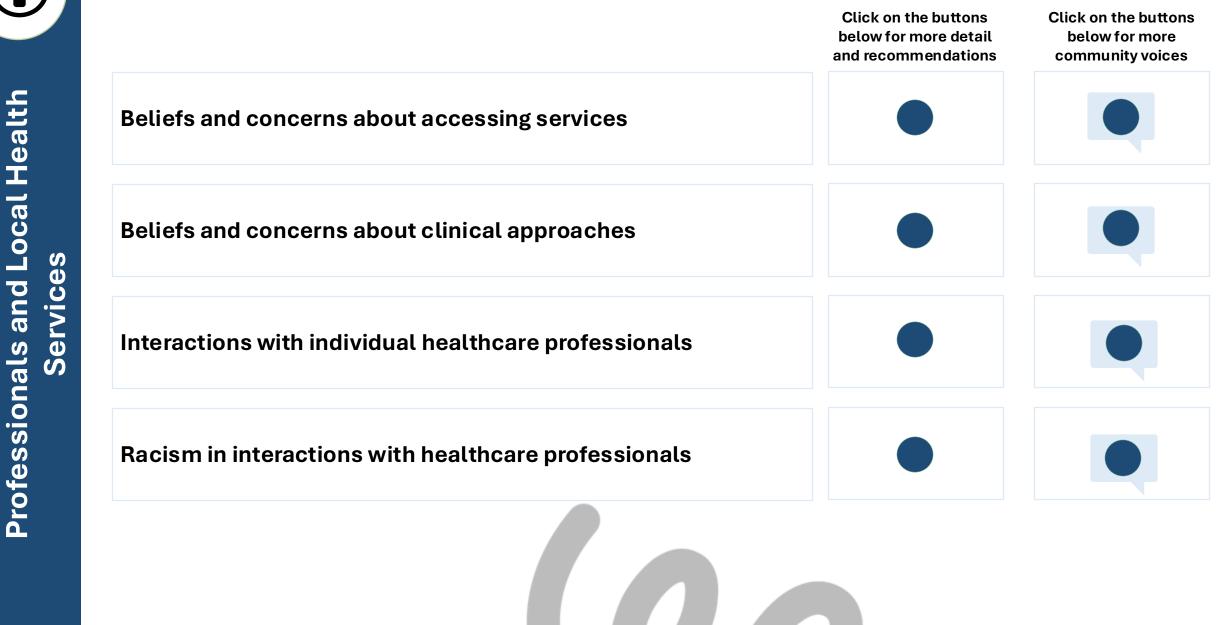
cal Health **Relationships with Healthcar** Φ and Ŭ Professionals



**Relationships with Healthcare** 

#### Find out more

MAB Adi Liko





# Impact of wider system and societal influences

They're trying to do what they've always done and expect a different result. And COVID has shown them...this is a problem that existed before COVID. Now you're forced to deal with it. Particularly the Black community, or minoritised communities, they're not going to participate in no survey, they rather die with all of their illness because they don't trust you. They don't want to change because you ain't changing... You change, they change.



Impact of wider system and societal

influences

## **Key Themes**





**Racism in healthcare:** Mistrust developed over generations driven by awareness of healthrelated racial discrimination, and the negative impact of racial oppression (and socioeconomical deprivation) on health outcomes.



**Healthcare system's service offering:** Inaccessibility of healthcare for certain marginalised or minoritised groups, with patients experiencing difficulties with obtaining appointments and getting care they need.



**Digitalisation of healthcare**: While community members perceive the digitalisation of healthcare as good and inevitable, they have concerns about the risk of digital exclusion.



**Data Sharing:** While the community accepts data sharing, they do have concerns about data being mismanaged/ leaked/ used against them.



## What we heard from participants



Impact of wider system and societal influences

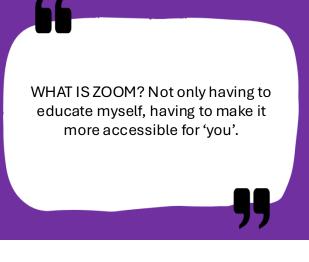
Ш



We're going to hand over our lives, probably to a white person or a South Asian person but there's no trust between us and those communities



Other agencies will go to your GP, as part of any investigations, big brother is always watching you



It'd be interesting if they also recognised and understood that racialised trauma and racism has an impact on our health as well. And that's probably one of the indicators, you know? And what can we do to kind of like, combat that?

## **Key Recommendations**

- 1. Create an anti-racism strategy for the healthcare system that would define ways to combat racism at different levels of healthcare provision, from the individual HCP to structural issues.
- 2. Streamline access to healthcare and reduce waiting times (include more options to secure appointments).
- 3. Adapt digital healthcare solutions to the needs of the elderly and other disadvantaged groups (difficulties to use new tech, to see/ write on small screens) to help them engage and avoid exacerbation of the existing health inequalities.
- 4. Provide clear and transparent information, either verbally, or in a written form, about who is collecting data (NHS, private company?), what the purpose is (per item of data collected), how data is handled and stored and which data protection policies and processes are in place.

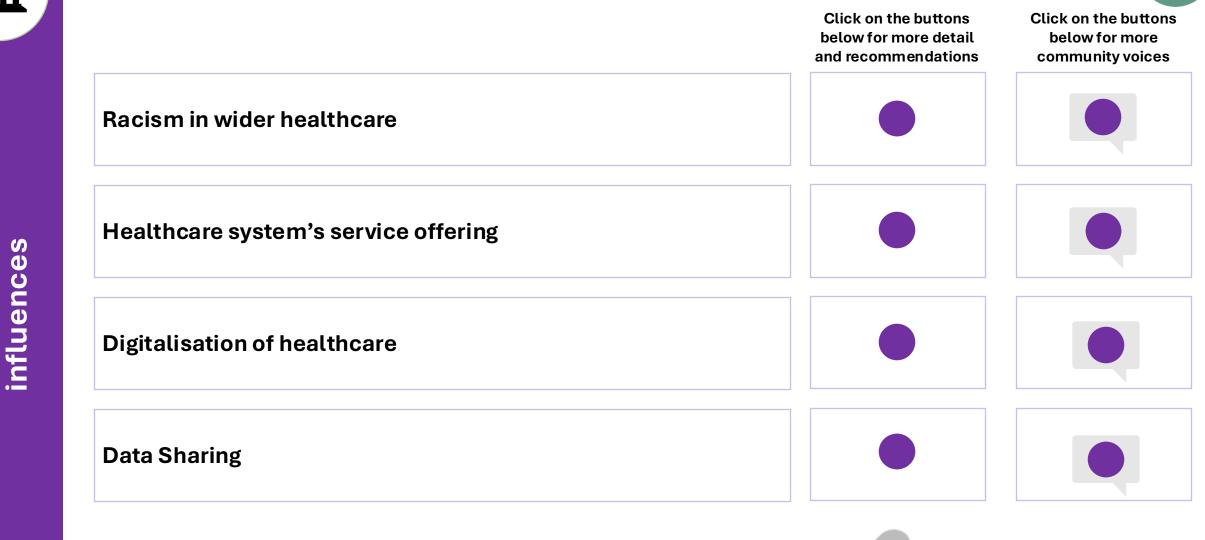


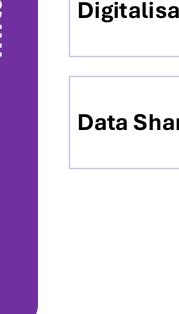




#### **Find out more**









#### Find out more



Please click the arrows below to find out more detail about the individual projects.

- 1. <u>Black African and Caribbean (BAAC) Obesity Insights (2020, Public Health Lewisham)</u>
- 2. <u>BAAC Mental Health Insights (2021, South East London CCG)</u>
- 3. <u>Diabetes Outcomes that matter to people in BAAC and South Asian communities (2022, South East London ICB)</u>
- 4. <u>Heart Valve Disease/ TAVI awareness and acceptability in BAAC communities (2022, Guy's and St. Thomas' Trust.</u>
- 5. <u>Stop BP Hypertension study in racially minoritised / deprived communities (2022, One London)</u>
- 6. <u>Acceptability of Vital 5 Check in BAAC, South Asian / economically deprived communities</u> (2023, King's Health Partners, South East London ICB)



#### Acknowledgments



We would like to extend our sincere thanks to the following individuals for their valuable contributions to this report:

- 1. Co-leads Dr. Nadine Fontaine-Palmer and Natalia Le Gal
- 2. Review and Editing Hillna Fontaine, Ritika Haresh Karamchandani and Adam Kamenetzky
- **3. Document Production** Lauryn Ipinson-Fleming and Ritika Haresh Karamchandani
- 4. And to all the **South East London residents** who made invaluable contributions to this report

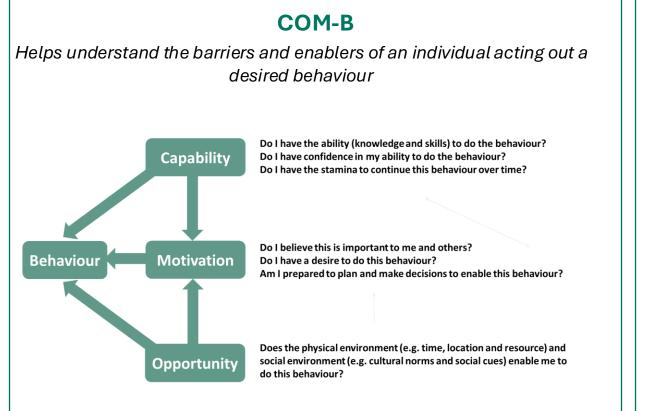


### Appendix



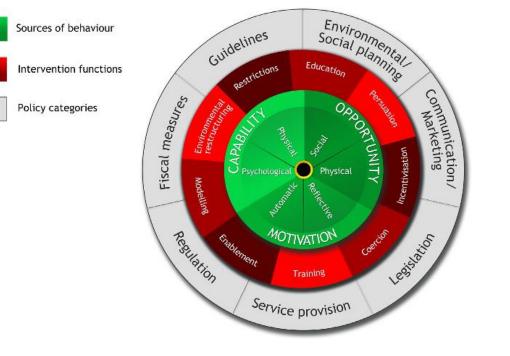
#### **Evidence-based approach (COM-B)**

This study is using the combined approaches of COM-B and the Behaviour Change Wheel to understand behaviour and design behaviour change interventions/ recommendations.



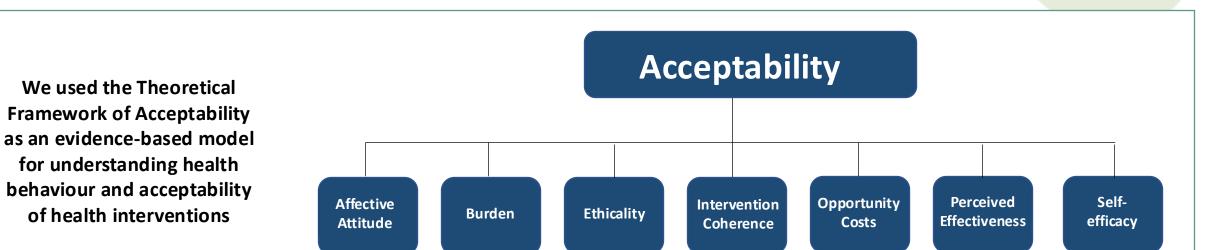
#### **Behaviour Change Wheel**

Helps translate the understanding of a behaviour into tangible behaviour change interventions/ recommendations which include tactical interventions (intervention functions) and broader system changes (policy categories)



#### **Return to previous location**

#### **Evidence-based approach (TFA)**



TFA construct	Definition	
Affective Attitude	How an individual feels about the intervention	
Burden	The perceived amount of effort that is required to participate in the intervention	
Ethicality	The extent to which the intervention has good fit with an individual's value system	
Intervention Coherence	The extent to which the participant understands the intervention and how it works	
Opportunity Costs	The extent to which benefits, profits or values must be given up to engage in the intervention	
Perceived Effectiveness	The extent to which the intervention is perceived as likely to achieve it's purpose	
Self-efficacy	The individual's confidence that they can perform the behaviour(s) required to participate in the intervention	



#### Health knowledge and awareness



Barriers/ Enablers + Solutions	Recommendations	
Barriers	Communication campaigns:	
Difficulty in spotting/ caring for/ talking about certain health conditions, e.g. mental health, hypertension, due to their hidden nature & unclear symptoms.	<ul> <li>Provide dedicated, condition-specific campaigns about prevalence, risk and care services (e.g. hypertension).</li> <li>Infuse health awareness campaigns with cultural codes of the community (e.g. music, language, visual images).</li> </ul>	
! General health awareness (need to exercise, to monitor BP), but lack of specific knowledge e.g. CVD/ HVD, level of physical exercise needed to remain healthy, what constitutes healthy body size/ weight.	<ul> <li>Include recognisable role models to enable people to self-identify with the communications and increase self-confidence.</li> <li>Within the campaigns include details that reflect the motivational factors of this community e.g. being the best for their family, holding</li> </ul>	
! Lack of knowledge about health support services and groups for and led by ethnic minorities.	<ul> <li>onto traditions but in a healthy way and looking good.</li> <li>Create resources that better communicate services available per healt condition - specific to the community.</li> </ul>	
! Limited knowledge about various NHS tools/ sources/ support.	<ul> <li>Create campaigns and resources that inform the community about health support services and groups for and led by ethnic minorities.</li> </ul>	
Enablers	General recommendations:	
+ Awareness of a higher risk of falling ill of certain conditions (e.g. sickle cell) among BAAC minority groups.	<ul> <li>Ensure that health advice offered is simple, easy to understand and</li> </ul>	
+ Awareness of the link between lifestyle: stress, diet and exercise, and health (diabetes, hypertension) (note - lower among younger people).	<ul> <li>apply, has positive elements and is adapted to various cultures and ethnicities of people that receive it.</li> <li>Provide bite-size video communication in various languages for those that have difficulties with English (writing (reading))</li> </ul>	
<ul> <li>Managing a health condition increases one's general engagement with health.</li> </ul>	that have difficulties with English/ writing/ reading.	

### Health knowledge and awareness

"

#### "

"

I think it is both, I think it should be explained, we just need to be made aware, because not everybody's aware..... well, I'm black person so, I'm more at risk of this thing than another thing... It's like, is it sickle cell, we're more, prone to that than the white people get it but we're, we're the ones that get that or higher risk of it or whatever side, you know, it needs to be made aware of. – Vital 5

I haven't got a clue what the symptoms are. So I'm gonna sit here. Not until something is wrong, then I go to the doctors, then that might come up. Or someone might say to me, when last have you had your blood pressure checked? And I'll be like, Oh, I didn't even think of that. - Hypertension It's a bit more scientific than that. Your lifestyle, stress lifestyle, the amount of sugar... salt intake in particular. -Hypertension

I've learned since high blood pressure is not good... and it can bring on all sorts of things, including strokes, etc. So managing it will be preventative, hopefully, to those things. - Hypertension



"

The short answer is yes, I think things should be highlighted for people of our community, and doctors or whoever checking you over, should be trained to know this, and highlight it. I think they get somebody who is from our community and say, I know, you know, people from your community tend to go higher risk of certain illnesses. - Vital 5

If I had the opportunity, if they would give it to me...they now have those selfmonitoring gadgets... I'd use those. -Diabetes

"

**Return to previous location** 



#### Individual beliefs and concerns



**Return to previous location** 



#### Individual beliefs and concerns

"

"

I think that it's really, really, really important to especially when you hit a certain age and your body begins to slow down. But you do start to go for more regular health, just maybe like, twice a year, or just going getting your blood pressure checked at the pharmacy. - Vital 5

"

"

Just give me the chance to express myself. I think, you know, just having that space to just... if I've got any concerns just allowing me to speak. I think that's what I would personally really, really like, from a medical person, basically, so I feel heard, and if I've got any concerns, to do your best to alleviate those concerns. But not making me feel like I was doing something wrong in having control over my own body and my own health. - HVD But there's a degree of complacency. Because a lot of people go, Oh, my aunt suffers with hypertension, diabetes, it's like, well, it's one of those things you could get, you know, you could have it, it's not the end of the world. -Hypertension

I've not been in the place to hear the advice. Sometimes people are willing to tell you things, but you're just not willing to hear it. - Mental Health Study "

"

I don't want to be a person that relies on quick fixes, versus doing what might be hardwired in myself to be a good steward of my own body. So there's something there about personal responsibility and accountability that I think about. - Diabetes

I think that it's really, really, really important to especially when you hit a certain age and your body begins to slow down. But you do start to go for more regular health, just maybe like, twice a year, or just going getting your blood pressure checked at the pharmacy. - Vital 5



#### Individual beliefs and concerns

"

"

MAB Adi Liko

But there's a degree of complacency. Because a lot of people go, 'Oh, my aunt suffers with hypertension, diabetes', it's like, well, it's one of those things you could get, you know, you could have it, it's not the end of the world. -Hypertension

"

I don't want to be a person that relies on quick fixes, versus doing what might be hardwired in myself to be a good steward of my own body. So there's something there about personal responsibility and accountability that I think about. - Diabetes

I've not been in the place to hear the advice. Sometimes people are willing to tell you things, but you're just not willing to hear it. - Mental Health Study Just give me the chance to express myself. I think, you know, just having that space

to just... if I've got any concerns just allowing me to speak. I think that's what I would personally really, really like, from a medical person, basically, so I feel heard, and if I've got any concerns, to do your best to alleviate those concerns. But not making me feel like I was doing something wrong in having control over my own body and my own health. - HVD

"





Barriers/Enablers + Solutions	Recommendations
Barriers	Supporting lifestyle change:
! Mental (ill) health impacting ability to engage with health care and lifestyle change.	<ul> <li>Work with community groups to develop and offer implementable lifestyle change advice and support.</li> <li>Run community health education campaigns focused on the possibility</li> </ul>
Physical (ill) health impacting ability to engage with health care and lifestyle change.	<ul> <li>Rull continuintly health education campaigns focused on the possibility of changing one's health trajectory to support self-efficacy.</li> <li>Provide culturally tailored and holistic resources and services to support lifestyle change that patients can self-select based on their ethnicity and preferences - to reinforce their autonomy and confidence.</li> <li>Ensure that lifestyle advice is inclusive and practical: culturally relevant, adapted to people's limited time and cognitive abilities, catering to the cost of living crises (e.g. meal plans with nutritional values based on traditional food types and using the terms that community uses).</li> <li>Embed physical activity opportunities into the everyday lifestyle of the community e.g. where they live, work and worship.</li> <li>Provide lifestyle change activities and advice adapted to particular</li> </ul>
! Difficulties in changing one's lifestyle to make it healthier or engage in proactive monitoring due to lack of time, family commitments, high cost/lack of financial resources.	
Previous - successful or failed - attempts at taking care of one's health (mental health, weight) inform beliefs about capability in changing one's lifestyle.	
! Social desirability bias a risk when assessing barriers to healthcare engagement and solutions to address them.	<ul> <li>target group (younger, older, men vs women etc).</li> <li>Apply cultural sensitivity in the design of physical activity programmes e.g. matching the gender of leaders and participants, allowing a flexible</li> </ul>
Enablers	dress code for women. ► Provide interactive health advice, for example through workshops –
+ Acceptability and desire for more frequent reminders for health check- ups/ testing from GP practices.	<ul> <li>they are perceived to be more effective.</li> <li>Offer holistic support e.g. practice-based culturally sensitive dieticians.</li> <li>Always provide a set of FAQs that may be useful to patients in the immediate days and weeks following the healthcare contact.</li> <li>Use behaviour change frameworks &amp; community outreach to develop and deploy health interventions to increase their chances of success.</li> </ul>
+ Motivation to engage in behaviour change when provided with clear information and follow ups.	
+ Behaviour change theory based services that help people change their lifestyle (e.g. establishing routines).	<ul> <li>Train HCPs in the ability to intuit and sensitively respond to social determinants that may impact people's health and capabilities to enact</li> </ul>
Return to previous location	<ul> <li>good health behaviours.</li> <li>Offer reminders to help people stick to the health activity they are being offered.</li> </ul>



MAB Adi Liko

Cost of living... people are really struggling. Some people are working two, three jobs as well. They really struggling, you know. So that 20 minutes exercise is something that is the last thing they think about. - Diabetes

"

"

Money resources very tight, and we tend to eat to fill our stomach. So people eat very heavy starch based food to fill their stomach. - Diabetes Exercise isn't really thought about in Asian families, not in older generations anyway. Traditionally women are busy looking after the house and the men... well maybe they just sit and do nothing at all. It's changing now a bit but I still think that exercise for us... in this country... isn't thought of the same way. But we're not tending to farms now, are we? The lifestyle has changed so we have to adapt. - Diabetes

My perception of that wouldn't be that: no, I'm not going to get immediate, fantastic benefits and sort out my health once and for all everything is just gonna be indicators and guidelines. But I will do the rest of my due diligence research and make it worthwhile. [BAAC] - Vital 5

"

I think it's good when it's convenient. And I just think that it's just sometimes I think I missed a few readings if I had been out. So I wasn't available, because I didn't provide a reading. So I didn't have my machine with me. So maybe just to build a bit more flexibility into when to provide the readings. - BP@Home

You know what? You need to slow down. You can't do everything. You need to learn to say no. And that's what I'm doing. And that's part of it. And then prioritising what I need to do going forward. Making time to say 'actually, today I'm going to go for a walk'. I've done in the last six weeks, I've done it, going for a walk. So that's really important is prioritisation. Putting ourselves first, realising me time is important. - Diabetes

99

**Return to previous location** 

#### Friends, family and wider social circle's impact



**Return to previous location** 

Barriers/ Enablers + Solutions	Recommendations	
Barriers	Including social elements in campaigns:	
! Culturally informed beliefs that certain health issues (e.g. mental health) and behaviours (e.g. focus on diet or stress management) are not important.	<ul> <li>Run community outreach campaigns by the community to reinforce social norms regarding effective health self-management.</li> <li>Frame benefits of health engagement concerning the impact of one's health on one's family/friends/ community.</li> </ul>	
! Culture and language inform lifestyle habits and health issues perception - e.g. types of foods eaten, portion sizes, perception of hypertension.	<ul> <li>Launch a stigma and health behaviour campaign designed and delivered by the community.</li> <li>Use real people from the community and their stories of health engagement/ behaviour change in health education campaigns.</li> </ul>	
! Gendered difference in health behaviours: women drive health behaviour change, men avoid healthcare system.		
Stigma and not wanting to be a burden impacting engagement (talking about/seeking treatment/ acting) on certain health conditions: obesity & mental health, but not others: e.g. hypertension, diabetes.	<ul> <li>Reinforcing practical social support:</li> <li>Allow for family/friends to be present when advice is provided to help consolidate during the consultation and ask questions.</li> </ul>	
Enablers	<ul> <li>Signpost to social support groups who share lived experiences &amp; culture particularly where people may not have family/ friends who can support them.</li> </ul>	
<ul> <li>Friends, family and peers play an important role in health management and recovery (e.g. encourage buying a home BP monitor, help with mental health issues or weight loss).</li> </ul>	Addressing gender differences:	
<ul> <li>Indirect experience of health issues, e.g. hypertension, diabetes, cardiovascular diseases, of friends and family positively impacts health engagement motivation.</li> </ul>	<ul> <li>Explore ways to reduce the gendered difference in healthcare engagement.</li> </ul>	

#### Impact of friends, family and wider culture

"



For me, I did go for one of these prediabetes courses where we did exercise and exercise was actually great. But the minute I stopped the course I stopped going... one really needs to motivate oneself and find someone who can help motivate you as well. - Diabetes

"

I've not personally used a home machine, but my parents have one. And they've always nagging me for the longest to have one at home. My sisters had one as well. And I've never heard them complain about it. - Hypertension That's actually the English translation. 'Don't make me stressed'. - Hypertension

What I find helpful is someone who sort of acts as an almost informal mentor. So I have a friend who's sort of been going through this... but he's slightly ahead. Sometimes we have these long conversations where we talk about all the different things we're doing. And it's immensely encouraging to have someone who's like you, who is going through the same thing. - Diabetes Childcare Companionship and encouragement will give me more confidence to go places with them. There are no creches in gyms, early morning, evenings, and weekends. - Obesity

I have a theory about men and health. Cause it's slightly different to women and health. If we feel pain, we're on it straightaway, because we kind of feel a bit more in tune with our bodies. I know there are men that are. But I found with most guys that have things going on with them, they will never do things straightaway. They tend to wait for a day or two. And I just sense it's because nobody wants to think they're going to be ill or they've got something serious wrong with them. - HVD



Individual and Community Factors

## Impact of friends, family and wider culture

In particular, our black men, they have a fear of what they're going to hear when they go to the doctor's. So it might be something simple, like just go for a blood pressure check, but they're scared they'll hear something else.- Hypertension

I do think that they are more broadly considered to be very negative words, stigmatised words. If you're obese, you're lazy. You eat crisps all night long. So I think that they create connotations about a person's character which are not necessarily true and can be quite shaming. - Obesity

66

Some people will be shocked into it, that it happens to a family member, or someone they really know. -Hypertension

I don't want the mental health to be on my record my medical records, because of the stigmatisation that can come with it. There's all kinds of background checks that you can do nowadays... especially for work. I feel like if my prospective employer was to do that rigorous, hard corporate background check, and it was just me against another candidate for a particular role, then I mean, even though it won't affect my current role, that could be the difference between me and them. - Mental Health Study

Especially in our black community as well, because someone will just automatically let you, 'okay, she's fat, she's got loads of problems'. So you know, 'you're over eating'. So that stigma is already there. And you don't, I personally don't necessarily want to compound or to bring more failure in the system. You kind of have a loss of self-confidence within yourself, because you're already feeling that low self-esteem. And then to go and say, 'Oh, I've got a problem with my heart'. Or somebody said, 'oh, yeah, yeah, it's your weight that is causing it', which, yes, that was a factor.

But then there are other factors. - HVD

I felt quite shamed by the doctors about weight because I had to lose some weight which I understood. But the way that was communicated to me was guite insensitive and made me feel a bit yucky. - Diabetes



#### Impact of friends, family and wider culture



When I told my mom about the miscarriages and that I felt it affected my mental health, the response wasn't what I think I needed at the time. And I think that was because of her like upbringing, how she grew up and her culture. It just wasn't what I wanted to hear at the time. -Mental Health Study

66

"

56

Your BMI is notoriously not a good indicator of health. So yeah, I think actually like in South Asian and Black communities, there needs to be a bit more sensitivity when it comes to talking about health and weight, and how to sort of handle that without being disrespectful or dismissive of the person and of their lived experience. This person knows what they eat this person knows how much they exercise. They don't really have much reason to lie to you. So going in now and sort of like rigid mindset and being like no, you need to lose weight, or no you need to stop eating X, Y, & Z. It's not helpful. If anything, it makes people not want to come back. - Vital 5

**Return to previous location** 

Individual and Community Factors

## Community involvement in healthcare provision



Barriers/Enablers + Solutions	Recommendations
Barriers	Development of health interventions:
<ul> <li>Decrease in community outreach and funding for the community (incl. VSCE sector) to support health-related outreach.</li> <li>Insufficient community involvement in the development and deployment of health interventions.</li> <li>Certain health topics are not considered appropriate (e.g. mental health) for pharmacies to handle.</li> <li>Preference for traditional health care settings (e.g. GP practices) for health checks vs community spaces (too informal, do not offer confidentiality) among some participants.</li> </ul>	<ul> <li>Organise and fund community involvement in the development of health interventions to ensure they are tailored, culturally appropriate and address heal inequality.</li> <li>Include and fund community partners - established VCSE leaders - in the development and delivery of health interventions. They can act as a bridge between communities and healthcare services, and as a learning partner for healthcare services.</li> <li>Increase the opportunity for healthcare interventions to be performed by 'community champions' (with sufficient and appropriate training).</li> </ul>
Acceptance of health services (e.g. screenings) being performed in public/ community/ mobile spaces if convenience, privacy, confidentiality and trained staff guaranteed.	<ul> <li>Offer healthcare prevention and support services that are adapted to a diversity of ethnic groups and run by the community, e.g. mental health support based on African and Caribbean approaches.</li> <li>Increase accessibility/ trust by providing health interventions through existing</li> </ul>
<ul> <li>Enablers</li> <li>+ Access to, experience with and appreciation of community pharmacy providing a range of health services, advice and addressing unmet need.</li> <li>+ Community (individuals and VCSE sector) willingness and capability to</li> </ul>	<ul> <li>Increase accessibility/ trust by providing health interventions through existing social structures of a community, where people regularly congregate (primary schools, mosques, churches).</li> <li>Capacity build community based organisations for health checks (where possible and health advice and guidance.</li> <li>Involve trusted community-based professionals from similar ethnic backgrounds to increase relatedness and decrease the language barrier.</li> </ul>
<ul> <li>contribute to help manage and improve the health of the community.</li> <li>Collaboration of healthcare system with communities in the developing solutions to address root causes of health inequality.</li> </ul>	<ul> <li>Provide community information campaigns educating people on the benefits of doing health checks in community spaces.</li> <li>When using community outreach stakeholders, e.g. pharmacies, provide information on why the staff is qualified/ how they have been trained to deliver areas that may appear out of their scope.</li> </ul>
<ul> <li>+ Healthcare prevention and support services adapted to a diversity of ethnic groups and run by the community.</li> <li>+ Regular community health education campaigns for all ages.</li> </ul>	<ul> <li>Offer training to all appropriate staff within community setting, not just manage</li> <li>Provide scripts for community health outreach Staff explaining the rationale and offering the opportunity to ask questions.</li> <li>Ensure private spaces are available to discuss health checks/ issues that may have stigma attached.</li> </ul>



Individual and Community Factors

"

Having things in my schools and community centres, literally anywhere, you can fit some sort of screening or health intervention or health check program, I think put it. Just because people who wouldn't even think about, you know, going to the doctor's to get something checked out. Might go odd. You know, what, just for a laugh, let me just jump on this bus for two seconds and see what see what they say, you know. - Vital 5

What they [the NHS] can do is collaborate with us on projects... if there are things that they clearly can do and the things that are difficult for us to do, we need help to promote our services...we can reach people that the NHS struggle to reach. They tell us, black people are hard to reach but, we reach them all the time. We can't not reach them, they're all around us. So, if we can reach them, I don't know why you find it hard to reach them. And so that suggests a problem and, as a resistance from our community, due to a lack of trust...- HVD I know it's not practical to bring it down to a pharmacy level. But if you break it down to the initial consultation are the chemists, they're getting more and more well equipped. And they're taking the pressure of GPS, but anything serious, you still got your GP. My chemist is down the bottom of my road, turn left here and we have good relationship amazing. A lot of things that I will go for GP for, I will call my chemist. I got his number on speed dial. - HVD

And there's, you know, the shadow of slavery... it's not a shadow, it's a real thing that everyone is dealing with. So these [community] circles, make a big difference to really being able to see what's going on, and understand how the system is set up to keep them down. Because you need to understand the oppression that you live in. - Mental Health Study You have churches and communities where they set up blood bank stations for people to give blood, they set up blood pressure testing, some even do heart testing, get out into the community. So I think it's a good thing. If it's solely at the doctor's, a lot of people won't go. - HVD

I'd like to see that [community based mental health services] offered to all black people in Lewisham so that they can come to a session like that. Not just one session, once is not enough... but some sessions like these and they can come for free and they can come regularly. And it's paid by the Council... because we get gas lit by the Council, by so many people...so I think that we all need this. - Mental Health Study

"



# Community involvement in healthcare provision

66

And wouldn't it be amazing if, you know, they go to these places, and they're like cooking together? And they're like, look, this is how I would normally make it. And there's someone there going,

'right? Okay, I know a lot about this stuff. I'm from your background, and I'm like your age.... but even I am diabetic. And my sugars are great now. I've got high blood pressure, but this is what I did. And now this is how I've made that chicken curry you made, let's make it together. Let's, you know, let's stand here with all the stuff...the spice mixes and everything. And let's talk about how we make these changes, and let's eat together'. - Diabetes

**9**9



network, peers.

### **Beliefs and concerns about accessing services**



Barriers/Enablers + Solutions	Recommendations
Barriers	Structural changes:
! Distrust, fear and anxiety in health system derived from negative experiences with healthcare system and HCP e.g. misdiagnosis, lack of follow-up, being spoken to in an off-putting way.	<ul> <li>Simplify and clarify healthcare pathways to ensure people are treated in an appropriate and timely manner and follow ups are provided.</li> <li>Ensure the integration of the follow up structure and accountability into any health intervention.</li> </ul>
! Negative discourse around NHS (being overwhelmed, staff being overworked, falling through the cracks) makes patients anxious to seek care and less likely to ask questions.	Training for HCPs:
! Complex health pathways reduce trust in health system and engagement in care.	<ul> <li>Cultural humility training for HCPs.</li> </ul>
	Challenging the established narrative:
Enablers	<ul> <li>Communication campaign highlighting positive stories of NHS taking</li> </ul>
+ Fear as a possible driving force for health engagement in conditions perceived as "critical" (e.g. heart valve disease).	<ul> <li>community outreach campaign to address a sense of burden when using health services.</li> </ul>
+ General appreciation of and trust in health care professionals, NHS processes, treatments and the health care offered by NHS.	
+ Positive attitude towards health interventions – blood pressure monitoring, exercise, screening.	
+ Willingness to engage in health education and personal research to validate the diagnosis and treatment, through internet, personal	

+ Repeated positive experiences of prompt and adequate health care provision and follow-up contribute to more trust and engagement.



## **Beliefs and concerns about accessing services**

# **Professionals and Local Health Relationships with Healthcar** Services

When I phoned up on the day, the appointments have already gone. I can't tell you the last time I've actually seen my doctor face to face because I can't get an appointment. Vital 5

"

**66** 

If you wait to be referred to a specialist, you're either going to be dead or it's going to cause so much damage waiting in queues to get anything done. It's just crazy unless you can go private. - HVD "

When they don't listen to you, and they force the different appointments on you without taking into account your previous health conditions, your time, your previous commitments -- it can be really exhausting because it's like - I work. You go to universityyou can't keep on top of meetings, on top of the you know, yearly appointments and you don't know what's gonna happen from this year to the next. - Vital 5

"

It made me want to fight more to get to whatever perspective I needed. It makes me more adamant to deal with those issues and deal with people so they know that they're thinking along the wrong route. - Mental Health Study "

"

I also thought of the NHS pressure, they don't need to see me. I don't need to waste their time, because, you know, they've got other more important things to do. - Hypertension

"

And whether it's a two-minute, threeminute film or something, someone's saying look, I know what you're thinking. I had the operation... here's me having the operation. And I feel better. I know you probably have your fears. But you know, I think that's what it is you want. To see before you believe it. - HVD



## **Beliefs and concerns about clinical approaches**



	Barriers/Enablers + Solutions	Recommendations
	Barriers	Encouraging patient feedback:
thcare Health	<ul> <li>BMI measurement percieved as incompatible with perceptions of healthy body size and weight.</li> </ul>	<ul> <li>Promote examples of where patient feedback has improved service delivery locally and nationally.</li> <li>Increase opportunities for patient feedback mechanisms and ensure 'you wild have been provided and an advected back mechanisms.</li> </ul>
lthcare   Health	! Concern about the impact of the pharmaceutical industry on the medicalisation of certain conditions.	said, we did' clearly communicated.
Healt ocal	! Concerns that medical treatments offered are primarily designed for White Europeans and not reflective of physiological differences with bodies of minoritised communities.	<ul> <li>Medication and standard measures:</li> <li>Provide recommended alternative solutions where possible instead of</li> </ul>
s with H and Lo rvices	Perception that, while necessary in some contexts, medication is overused to the detriment of support for lifestyle changes in the management of certain conditions (e.g. hypertension).	<ul> <li>medication.</li> <li>Review medication more often.</li> <li>Clarify and make explicit any financial incentives from pharmaceutical companies - locally and nationally.</li> </ul>
hips nals Se	! Concerns about the impact of sharing negative feedback - e.g. the health system will not act upon it, it may have negative consequences for the person.	<ul> <li>Review medication approaches for the BAAC community.</li> <li>Support inclusive health research that analyses the impact of medication on a variety of ethnicities.</li> <li>Adopt culturally appropriate weight management practices to further</li> </ul>
ion: sio	Enablers	help patients be successful.
Relations Profession	+ Acceptance of health screening, advice or treatment when offered explanation from a trusted source.	
A L	+ Perceived importance to challenge healthcare professionals and be an advocate for one's health (but unequal resources to do so, young people	

and people with immigrant background disadvantaged).



**Professionals and Local Health** 

Services

**Relationships with Healthcare** 

## Beliefs and concerns about clinical approaches

"

"

What I'd like to say is, if you go to the health check, and they tell you in this way that 'oh, you might have a heart attack, you might have a stroke'. There are some of us that might have anxiety hearing this, it might make us more ill. So maybe they explain the whole procedure and educate us on it. And then we might understand and might go, "Okay, we have to take action". But if we're told straightaway that "Oh, you're going to have a heart attack", I'm going to worry about and probably have a heart attack. - Vital 5

#### When you're in an emotional resilience, healing space, as soon as you open your mouth and start talking about your experience, somebody else is going through the same thing, and you just automatically feel supported before you go any further. You're saying it's not me, I'm not on my own, you can work as a group, you learn techniques and strategies. And that's the beauty of these people. Black people need some way to be able to talk about their experiences and receive some coping strategies. - Mental Health Study

I don't believe that the BMI is based in science and all of that type of stuff. - Diabetes

Before I went to my last medical journey, I didn't really have these in my head. But now that I've gone through it, I'm acutely aware and like hyper vigilant. And if me being hyper vigilant means that I ask 20 extra questions, then you better answer my 20 questions. - Diabetes I would regard heart valve disease to a certain degree like sickle cell and all the others. I think it depends on, we as a race of people, our DNA is not the same as others. And I think we have to accept that. And our experience is different to others as well. And the pressures that we encounter, especially here and the conditions and so forth, accumulate to a lot of things happening to us. - HVD

"

I used to be very compliant, but I've had multiple health issues. I've become more inquisitive, finding out what it's good for me and I can navigate better. - Diabetes

"



## Interactions with individual HCPs



#### **Barriers/Enablers + Solutions**

#### Barriers

- ! Feeling that HCPs do not respect one's values, culture and traditions.
- ! Advice offered is not applicable, because: too jargony/fear-based/not adapted to culture and ethnicity of the person.
- ! Entrenched hierarchy gives healthcare practitioners power over patients.
- ! Lack of flexibility of appointments at GPs (always in working days, no choice of time, in locations geographically far, only one issue to discuss).
- ! Lack of interest and support in alternative/ traditional/ homeopathic solutions within traditional health care offered.
- ! Variability in possibilities to build relationship and trust, and to regularly engage with the same HCP.

#### Enablers

- + Trusted relationship with HCP providing empathic, respectful and human-centered care mitigates distrust in the wider system/ fear from the diagnosis and helps with engagement.
- + Autonomy enabled by drop-in services, late night appointments and flexibility in accessing care improves engagement.
- + Existence of patient-focused services and tools at GPs (e.g. BP reading machine).
- + HCPs with similar ethnicity and/or gender can (for some people) increase trust and engagement due to assumption of understanding of lived experiences and more culturally-sensitive communication styles.
- + Culturally-sensitive and human centred behaviours in HCPs e.g. Ethnicity-conscious, empathic communication, emphasis of individual care and patient benefits/ needs to increase engagement/ encourage behaviour change.
- + Culturally-sensitive, practical and consistent guidance regarding lifestyle changes to implement (e.g. food, exercise).
- + Demonstrated awareness of physiological differences or greater health risks among minorities by HCP.
- + Interest in discussing and incorporating alternative/traditional/homeopathic/ethnicity-based solutions within traditional care offered for most conditions (with the exception of HVD).
- + HCP of similar ethnicity (for some participants).
- + HCP referring to and using medical records during consultations.
- + Holistic support including easy access to practice-based culturally-sensitive nutritionists and dieticians.
- + Opportunities to discuss alternative treatments safely and respectfully with HCPs.
- + Opportunities to discuss social determinants of ill-health with HCP.



## Interactions with individual HCPs



#### Reccomendations

#### For the healthcare system:

- Provide training on cultural sensitivity/ humility and the impact of systemic racism to HCPs to help them integrate ethnorelative (vs. ethnocentric) perspectives of ethnicity, religion and culture in patient engagement.
- Provide training on inclusive communication to give HCPs the skills to make patients comfortable and to encourage them to have an honest discussion about their health.
- Ensure checks and advice provided are comprehensive, delivered (either verbally or in a written manner) in a clear, jargon-free, competent and confident manner with patients are provided with answers to their critical questions/ fears.
- ► Offer options of HCPs of similar ethnicity (important for some community members).
- ► Support patients in maintaining longer-term relationship with the same GP.
- ► Offer more flexibility in GP appointments.
- Offer options to discuss alternative solutions with the GP as this may allow patients to feel understood and more likely to take up classical healthcare offering.



## Interactions with individual HCPs

"



**Professionals and Local Health** Relationships with Healthcar Services

I felt like I was dismissed and spoken down to as well. They were still offering me what I said I don't need so I thought it was more or less a box ticking exercise. -Mental Health Study

"

I think what makes it difficult receiving from the doctors is the diet element. Because they're telling me I got to eat this, I got to eat that... they don't know what kind of food I eat, they don't understand. - Diabetes

6

But being aware of the community that you serve. What does that community that you're serving look like. So then be more educated about them... about foods, about culture, about all of those things, because you can then better support. Because when somebody is coming to you, you can show that understanding.- Diabetes

**9**9

When communicating with black people... we use different language 'you will die, you will not see your grandchildren' and use real life case studies. Stroke means that you can't do XYZ, there's all these real knock-on effects. - Hypertension



"

And seeing me as a human being, you know, being aware that if you're overweight, that you might feel a bit of embarrassment. I expect them to be anticipating that I don't expect to have to tell them, 'hey, look woah careful with your language there'. So, sensitivity, when you go into a doctor's and you've got medical issues, it's normally frightening. - Diabetes

"

You can tell a doctor who tells you what to do and the one that converses with you right? Someone who takes the time to explain things to you, who listens to you, you know, and takes into consideration your views. - Diabetes



## **Racism in interactions with healthcare professionals**



		•
	Barriers/ Enablers + Solutions	Recommendations
	Barriers	Training and care delivery:
Relationships with Healthcare Professionals and Local Health Services	<ul> <li>Experiences of interpersonal racism and discrimination at the hands of healthcare practitioners leading to distrust, avoidance of the health system and reduce willingness to engage in any healthcare intervention.</li> <li>Perception that the impact of racialised trauma on Black health outcomes is not appropriately considered.</li> </ul>	<ul> <li>Train HCPs in culturally-sensitiand discuss the impacts of racia treatment options (cultural hum)</li> <li>Train healthcare professionals inhave difficult conversations about interacting with the community</li> <li>Provide additional training and professionals to increase wellbet tools to advocate on behalf of ot community.</li> <li>Review and ensure the diversity</li> <li>Practical support:</li> <li>Offer the opportunity to connect BAAC HCPs for those who need by Provide African-centred therapt discrimination-related mental herapt discrimination-related mental herapt discrimination in the device ensure authenticity and account</li> </ul>

#### CPs in culturally-sensitive practices including ability to intuit uss the impacts of racial trauma on health outcomes and nt options (cultural humility training).

- althcare professionals in skills, language, and confidence to ficult conversations about race with each other, and when ng with the community.
- additional training and support for BAAC healthcare nals to increase wellbeing and engagement as well as provide dvocate on behalf of other BAAC professionals and the nity.
- and ensure the diversity of staff delivering care.

#### support:

- opportunity to connect BAAC community members with CPs for those who need it.
- African-centred therapeutic groups for moderate and racial nation-related mental health.

#### ity involvement:

communities in the development of antiracism interventions to uthenticity and accountability.



## **Racism in interactions with HCPs**



She was white. I wouldn't say intimidating, but I felt like I had to explain my culture a bit and where I was coming from for her to understand. - Mental Health Study

"

"

More than anything. And there's also the systemic issue. structural racism. I'm very, very aware of it. I know that doctors are under pressure. I believe that the wider system does, either actively, sometimes disadvantages us or through negligence as black people. And those are all things that kind of ...I take into consideration when I'm deciding whether or not I'm going to take up an option. - HVD

"

## "

Taking into consideration the fact that, you know, there are certain positions that are just really stressful... people who are underemployed, and, you know, they have different stresses, therefore, they're gonna have poor health outcomes. And just being creative around that. -Diabetes

## **Racism in wider healthcare**



al	
iet	Barriers/ Enablers + Solutions
О О	Barriers
npact of wider system and societal influences	! Mistrust developed over generations driven by awareness of health- related racial discrimination (e.g. inequitable/ dangerous health research in minoritised communities).
stem nces	! Negative impact of racial oppression (and socioeconomical deprivation) on health outcomes e.g. mental health.
er system nfluences	Enablers
wide in	+ Healthcare system hosting an open and honest conversation about the impact of racial trauma on health outcomes.
ct of	
npa	

	Public discourse and research:
reness of health- rous health research	from the individual HCP to structural issues.
omical deprivation)	<ul> <li>Support wider efforts to understand and address social determinants of health.</li> </ul>

Recommendations

 Continue to invest in research on the healthcare experiences of people from racially minoritised backgrounds and racism's impact on health outcomes and better signpost where this has taken place to increase trust.



## Racism in wider healthcare

They're trying to do what they've always done and expect a different result. And COVID has shown them...this is a problem that existed before COVID. Now you're forced to deal with it. Particularly the black community, or minoritised communities, they're not going to participate in no survey, they'd rather die with all of their illness because they don't trust you. And there's also the systemic issue, structural racism. I'm very, very aware of it. I know that doctors are under pressure. I believe that the wider system does disadvantage us through negligence. And those are all things that kind of... I take into consideration when I'm deciding whether or not I'm going to take up an option. - Diabetes I think that's why our community don't engage, it's the same reason why we don't engage with giving blood. And the testicular cancer checks, it's a cultural thing, I think. We just need to be educated and we need trust. We're going to hand over our lives, probably to a white person or a South Asian person but there's no trust between us and those communities . -HVD

"

Because I essentially don't have that kind of wonderful switch ability to kind of just suck it up and deal with people being like racist or bigoted. And I'm terrified. So yeah, emotional resilience and healing would be so beneficial for those in work. -Mental Health Study It'd be interesting if they also recognised and understood that racialised trauma and racism has an impact on our health as well. And that's probably one of the indicators, you know? And what can we do to kind of like, combat that? -Hypertension



## Healthcare system's service offering



	Barriers/ Enablers + Solutions	Recommendations
Γ	Barriers	Standard healthcare offering:
	<ul> <li>Difficulties in getting appointments and support for health issues.</li> <li>Inaccessibility of healthcare for people with certain profile, e.g. financial hardship, childcare responsibilities, precarious immigration status/ not speaking English, those experiencing domestic violence, and with mental illness.</li> <li>Insufficient/ inadequate preventative health care provision, including tackling fundamental causes of illhealth such as housing, with negative results for the health of the population, in particular for those with multi-morbidity and mental illness.</li> <li>Issues with quality and availability of NHS services.</li> </ul>	<ul> <li>Streamline access to healthcare arroptions to secure appointments).</li> <li>Offer healthcare engagement opporties.</li> <li>Offer health services in multiple lead (including outside 9-5).</li> <li>Provide out of hours drop-in clinic or monitoring of specific condition</li> <li>Enable patients to discuss multiple</li> <li>Equip GPs with more self-service I monitors).</li> <li>Create default health checks for engle.</li> <li>Integrate alternative/ traditional/traditional healthcare offered.</li> </ul>
	+ Joining up mental health services with housing and employment ones to offer a better treatment path and reduce access barriers.	System-level:
	<ul> <li>+ More options to secure appointments.</li> <li>+ Physical environment for therapeutic services that is welcoming.</li> </ul>	<ul> <li>Provide more system level preven fundamental causes of ill health, e</li> <li>Ensure that sign-posting resources e.g. housing or employment.</li> <li>Link mental health services with 1</li> </ul>

althcare and reduce waiting times (include more ntments).

- ement opportunities for people with minoritised
- multiple locations and at various time of the day
- op-in clinics and appointments for health checks c conditions (e.g. BP).
- ss multiple issues per visit.
- If-service health monitoring devices (e.g. BP
- necks for every practice visit for at-risk patients
- raditional/homeopathic solutions within ffered.
- vel preventative health care, with a focus on ill health, e.g. housing.
- g resources include references to social support ment.
- vices with housing and employment ones to offer and reduce access barriers.



## Healthcare system's service offering

"



I have been informed that GPs are stretched, services are stretched. I found that when I've been in pain, severe pain, I've been told to call for an appointment in a week's time. So, there's almost a giving up of the GP actually, right now. -Hypertension

"

I don't trust NHS or HCPs. I don't think anybody should; I think that they are clearly overworked, and underpaid. And that will impact the level of care that you end up receiving, especially in lowincome communities where they will just send you in and out. - Vital 5

"

It was a struggle. It wasn't easy. I'm not feeling confident in them in the process. In the end it was private, but my employer had to pay for. So, the NHS could n't really provide what I needed. - Mental Health Study The GP has maximum six minutes of me. Whether that's changed, I don't know. And when my time is up... there are things that he or she will do that tells me time up. - Diabetes In some of the communities where we live, you will find somebody like Harrogate, the amount of takeaway shops with some of the unhealthy meals they're sort of selling. There's no coincidence. - Hypertension

"

There is a huge difference in what people get in their GP practice. - Hypertension

"

"

societal

Impact of wider system and

(C) (C) (C)

influenc

## **Digitalisation of health services**

#### **Barriers/Enablers + Solutions**

#### **Barriers**

- Lack of possibility to contact a human when needed, while using digitalised health services.
- ! Limited knowledge about where to express any concerns regarding data management.
- ! Risk of digital exclusion and inequality with the advent of personalised tech-based health management solutions, as some people do not have the necessary skills.
- ! Preference for face-to-face appointments that offer opportunities to discuss multiple issues with GPs, especially for wider/ complex needs.
- ! Preference for information on paper to be able to refer back to it.
- ! Some concerns about the reliability and trustworthiness of at-home solutions/ devices for health management.

#### Enablers

- + Perception that digital data saving is more secure than paper.
- + Personalised, at-home, tech-based health management solutions (phone, chat, app, device) perceived positively as convenient, flexible, inevitable.
- + Adaptation of the digital healthcare solutions to the needs of the elderly and other disadvantaged groups (difficulties to use new tech, to see/ write on small screens) to help them engage and avoid exacerbation of the existing health inequalities.
- + Clear information on data collection and management: what is collected, why, who manages data and the benefits for the patient of health data storage and flows.
- + Community-based support to build digital skills needed, including utilising young people (with higher technology adoption) to support wider community accept and use digital solutions.
- + Offering a variety of options and autonomy to choose between f2f and digital.
- + Transparent procedures to give and withdraw consent for health staff to use/ access/ manage health data.

#### Recommendations

#### Communicating about digital / at home healthcare solutions:

- Promote the broader benefits of digital technology/self-management solutions for the individual and for the community via communication campaigns, emphasising their reliability.
- Communicate on specific benefits of a digital/ at home treatment or health activity (e.g. BP monitoring), nd link it to the benefits to quality of life and the ability to remain healthy for family and friends.
- ▶ Promote the convenience and flexibility of using at home/ digital healthcare solutions vs visiting the GP.
- ▶ Provide clear signposting, accessible to all people in the community, about how to access digital/at-home healthcare devices & services.
- ▶ Use a variety of means to communicate the advantages of the solutions: video, online, paper.



## **Digitalisation of health services**

#### Recommendations

#### Supporting adoption:

- Ensure the services are branded with NHS/GPs colours and logos and there is clear information about the source to communicate they come from a trustworthy source/avoid the perception of them being fraudulent.
- ▶ Use examples of people in the community to promote the adoption of at-home health devices/ digital services.
- ▶ Use the social norm where appropriate to showcase the solution being successfully used in the community (e.g. sharing the num ber of users).
- ▶ Provide opportunities for people to personalise the solutions to their needs: e.g. choosing the frequency and time of reminders.
- ► Offer solutions that are adaptable to a variety of body types and sizes.

#### Ensuring human touch:

- Ensure that point of diagnosis/ treatment discussions are conducted face to face (and provide patients with range of treatment options, f2f and digital. to increase sense of autonomy).
- Start digital/ at home health solutions with human engagement first (e.g. a call from a GP), include periodic checks by a human and offer a possibility to access human assistance in an effortless way throughout.
- ▶ Provide opportunity to write feedback/ questions and have them answered by the person's chosen HCP (GP, pharmacist).
- ▶ Integrate various support services to provide human feedback (e.g. health navigator rather than GP/ pharmacist).

#### Ensuring digital inclusion:

- Adapt digital healthcare solutions to the needs of the elderly and other disadvantaged groups (difficulties to use new tech, to see/ write on small screens) to help them engage and avoid exacerbation of the existing health inequalities.
- ▶ Offer digital/ at home health management solutions skills training targeted at groups at high risk of digital inequality.
- Provide community support to build digital skills needed, including utilising young people (with higher technology adoption) to support wider community adoption.
- Offer paper/non-digital options for those that prefer it.



## Digitalisation of health services

"



Impact of wider system and societal S Ð influenc

WHAT IS ZOOM? Not only having to educate myself, having to make it more accessible for 'you'. The fact that this meeting is on Teams will have been too much for his Mum. Digital makes things more accessible but only for some. -Hypertension

66

So, it's convenient, obviously, rather than having to go to the doctor daily to get it done? - BP@Home It's personal preference, isn't it? I think we should have a choice. - Hypertension

"

If I've got a problem, when you used to go to the doctors, you know, they used to give you an exam. They might look at your ears, look at your eyes, look into your eyes, and they can tell certain things when they look into you. But if you're, you know, you're doing it on an app is not easily readable. - BP@Home I don't have a problem with that, if it means that I don't have to be leaving my house and trek into the doctor's every five minutes. And my blood pressure has been managed. I don't mind. -Hypertension

"

I just got a message, and it was explained to me through a text. At first, I just saw the WhatsApp message came up on my phone. And I didn't know where it came from. So, I didn't respond to it for a while, because I wasn't sure if it were... if it was authentic or not. - Hypertension

"

## **Data Sharing**



al	
iet	Barriers/ Enablers + Solutions
С О	Barriers
npact of wider system and societal influences	! Concerns about data being mismanaged/ leaked/ mixed up/ used against the patient.
s S	Enablers
er system nfluences	+ Acceptance of a broad, multi-factor questionnaire when performing a health check - provided requests are considered "reasonable".
' sy lue	+ Acceptance of NHS/ GP holding and managing one's health data.
ider inf	<ul> <li>Recognition of the need to share one's health data to benefit community</li> <li>and improve health care for oneself and others.</li> </ul>
of w	
act e	
npa	

	General recommendations:	
ised against	<ul> <li>Ensure confidentiality is embedded in all healthcare outreach activities.</li> </ul>	
	<ul> <li>Clearly communicate the individual and community benefits (e.g. improving the health services for others) of sharing data, its safety and people's autonomy in doing so.</li> </ul>	
orming a ata.	<ul> <li>Provide clear and transparent information, either verbally, or in a written form, about who is collecting data (NHS, private company?), what the purpose is (per item of data collected), how data is handled and</li> </ul>	

stored, and which data protection policies and processes are in place.

► Create and implement clear procedures to give and withdraw consent

for health staff to use/ access/ manage health data.

Recommendations



## **Data Sharing**



66 Other agencies will go to your GP, as part of any investigations, big brother is always watching you. - Hypertension

77