The Birmingham and Lewisham African and Caribbean Health Inequalities Review (BLACHIR)

Lewisham Community Consultation

Karl Murray 24 February 2022 Kinaraa CIC

Birmingham and Lewisham African and Caribbean Health Inequalities Review (BLACHIR)

Acknowledgement

We wish to gratefully acknowledge the contributions of many individuals who had various roles in the development and implementation of the research. Special thanks and appreciation are extended to the collaborative partnership organisations, who, if not for their energy and organising skills, we would never have reached the participants and undertake the level of write-up that was required. In particular, thanks and appreciation go to:

- Husseina Hamza and Rose Euphrase (Red Ribbon Living Well)
- Leon Thompson and Francine Daley (360 Lifestyle Support Network)
- Ray Black and Joseph Oladuso (Action for Community Development)

The coordination and pulling together of the team were made easy through the work of Barbara Gray, Urban Dandelion, on behalf of Kinaraa CIC.

We wish to thank the participants who took time out in the evenings, including during childcare circumstances, to engage in dialogue with strangers. Being willing to shar your thoughts in open sessions with groups of up to eight people unknown to you cannot be easy. So, we thank them for so doing and for their honesty and willingness to share some personal experiences.

Our thanks and appreciation go to Lisa Fannon, Public Health Training and Development Manager, Communities Directorate and Dr Catherine Mbema, Director of Public Health, Public Health Community Services Directorate, Lewisham Council, for their faith and confidence in the process.

Finally, the responsibility for the sense made of the voices that helped to shape our understanding rests with me, the author, and hope I have done justice to what we have heard and not strayed too far from the shared experiences that has shaped the lives of so many residents living in Lewisham as we go forward.

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Citation
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Murray, K (2022), *Birmingham and Lewisham African and Caribbean Health Inequalities Review (BLACHIR): Lewisham Community Consultation*; Kinaraa CIC

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Executive Summary

The Birmingham and Lewisham African and Caribbean Health Inequalities Review (BLACHIR) is a joint project between Lewisham Council and Birmingham City Council to understand and take action on long-standing health inequalities for people of Black African and Caribbean heritage. The BLACHIR External Advisory Board summarises well the context and background to the project:

"*Birmingham and Lewisham Public Health Divisions share a joint aspiration to address ethnic inequalities, through an increased understanding, appreciation, and engagement with Black, Asian, and Minority Ethnic (BAME) groups. This has resulted in a partnership between the two Public Health Divisions to share knowledge and resources through a collaborative review process to, initially, focus on the Black African and Black Caribbean communities, to enable a more detailed and culturally sensitive approach*"[1].

The overarching BLACHIR Review took a thematic approach which explored specific topics to evidence needs and to recommend actions that should drive sustainable change. The themes have been clustered around the eight areas indicated below, which informed the context for the consultation conversations:

1) Structural racism and discrimination
2) Pregnancy and early years (0 to five years of age)
3) Childhood and being a young person (ages five to 25 years of age)
4) Staying healthy as you age (from 40 years of age and onwards)
5) Mental health and wellbeing
6) Habits/behaviours that influence your health
7) Social and economic influences (e.g. education, housing, employment, crime)
8) Access to health care and managing health conditions

Within the Lewisham context, the engagement process was commissioned by Lewisham Council's Director of Public Health as part of a wider consultation process within the Black African and Caribbean communities led by a collaborative of Lewisham based Black third sector organisations, under the guidance of Kinaraa CIC. The approach was to focus on ensuring the lived experiences and voices of Lewisham's Black African and Caribbean communities was heard. Putting this into context, the Lewisham Health and Wellbeing Strategy states: "*Health inequalities are unfair and avoidable differences in health and wellbeing. Within Lewisham, and nationally, we know that people of Black African and Caribbean heritage suffer from health inequalities and this work aims to address them to make life fair.*" It is against this background that this consultation report is to be read and understood.

[1] The Birmingham and Lewisham African and Caribbean Health Inequalities Review (BLACHIR): External Advisory Board, July 2020

However, it is important to get a better understanding of the Lewisham context that has prompted the need to explore health inequalities as it relates to Black African and Caribbean residents living in the borough.

The research included both qualitative and quantitative approaches, through structured 1-2-1 and focus group interviews and survey questionnaire. Some basic information was captured from each approach, which provided demographic and contextual information on the key characteristics of respondents.

Three organisations were engaged in the direct delivery of the field research (1-2-1 interviews and focus groups)[2]. Through their work and engagement, six (6) focus group sessions were conducted and five (5) 1-2-1 depth interviews completed.

As a result of the process, 33 participants engaged in the focus group sessions (28) and 1-2-1 sessions (5) while the online survey questionnaire attracted a further 55 respondents. Thus reaching 88 participants from which the report analysis is based.

Key findings

Of the eight (8) themes identified to tackle race inequalities in Birmingham and Lewisham, the top three themes identified as priorities by respondents to the online questionnaire were:

1. Structural racism and discrimination;
2. Mental health; and
3. Staying healthy as you age.

Respondents were asked to rank the key actions identified by the phase 1 academic review reports, from which the top three were identified. Under each theme, they are:

Theme 1: Structural racism and discrimination

- Action 2 – Recognition of racism as an adverse childhood experience, was the most urgent action
- Action 1 – Removal of colour language coding in data collection, was the second priority; and
- Action 4 – Council and partners need to integrate diversity into education to reflect diverse cultures - as the third priority

Theme 2: Pregnancy and early years (0 to five years of age)

- Action 1: Develop culturally competent health professionals' training curriculum
- Action 2: Accurate collection and disaggregation of data by ethnicity
- Action 3: Build an online tool that can allow health professionals to rapidly access and compare pathways.

[2] The three organisations involved were Red Ribbon Living Well, 360 SLN and Action for Community Development (AfCD). Appendix 2 provides further details on each organisation.

Theme 3: Childhood and being a young person (ages five to 25 years of age)

- Action 1: Specific intervention and support at key transition periods
- Action 2: Councils and partners to work with culturally appropriate services to support young people through mental health concerns
- Action 4: Work to be conducted to address the disproportionate levels and impacts of economic deprivation for Black African and Black Caribbean communities.

Theme 4: Staying healthy as you age (from 40 years of age and onwards)

- Action 1: Accessibility – ensure good quality hospital and social care is accessible to all older people of African and Caribbean or Black-mixed ethnicity;
- Action 2: Cultural competency – provide awareness training for care home workers focused on older individuals of African, Caribbean or Black-mixed ethnicity;
- Action 3: Unpaid care – understand the number of unpaid carers who are of African and Caribbean heritage.

Theme 5: Mental health and wellbeing

- Action 1: Inclusion and mental health - raise awareness of the disparities African and Caribbean communities face in mental health, care and treatment through explicit education and engagement programmes;
- Action 2: Cultural Competency in mental healthcare - require all mental health providers to demonstrate how patient and carer perspectives are being used to inform mental healthcare service improvements;
- Action 3: Community support - support community organisations and groups to develop and facilitate support groups within the African and Caribbean communities.

Theme 6: Habits/behaviours that influence your health

- Action 1: Develop a positive health behaviour programme that does not require pharmaceutical intervention;
- Action 2: Recognise impact of racial trauma on health behaviours of migrant populations;
- Action 3: Investment in organisations and groups within and across communities outside statutory Local Authority and health providers.

Theme 7: Social and economic influences (e.g. education, housing, employment, crime)

- Action 1: Acknowledging culture and religion as integral aspects of health;
- Action 2: The Council and local authorities work with government agencies and institutions to eradicate issues ethnic minorities face when in contact with the justice system;
- Action 3: There is a need to conduct more research to understand these issues better and devise strategies to implement at community levels to address structural issues.

Theme 8: Access to health care and managing health conditions

- Action 2 – undertake qualitative research to understand and overcome negative perceptions and experiences between Black African/Caribbean communities and health services in accessing care, including the influence of structural racism and discrimination;
- Action 1 - All commissioned services (existing and new) to collect and analyse data across specific ethnicities and gender for all Key performance indicators;
- Action 3 - Ensure prevention services are equitable, appropriate and take into account the needs of Black African and Black Caribbean communities

Using a thematic approach to clustering, six themes emerged that were consistently referenced across the sessions, which added further weight to the ranked priority Actions indicated through the prioritisation process. They were:

1. Accessibility to GPs (i.e. waiting time, booking appointments etc)
2. Trusted and accurate information (including communication and language issues)
3. Immigration status
4. Cultural expectations (i.e cultural insensitivity; taboos and stigma etc)
5. Care home v 'home care' concerns
6. Wider social and economic factors (ie. Impact of poor housing, traffic congestion and crime)

There was a strong view that the 'community bridges', seen as the roles that voluntary and community organisations could play, was critical in the roll out process, especially as they represent folks who are the recipient of services. It was noticeable that throughout the focus group conversations participants wanted services 'closer on the ground' to them; to have service practitioners able to identify culturally with their needs and to see good quality care services in place. The key here was not segregated provisions but good quality equitable services, especially services being offered to those who were elderly, those living with a disability and those living with long term diseases and condition such as HIV. All of these being concerns raised by the JSNA and included within the Health and Wellbeing Strategy. Far from being antagonistic, the reflected voices from the participation pool of close on 90 respondents, indicated very much a consistency in identifying key actions that should be prioritised.

In many ways, and perhaps not too surprising, participants on the whole indicated that any changes envisaged need to be ones that improve local resident situation and not just 'tick box' exercises and platitudes. As one person wrote in responding to the questionnaire on Theme 4: *"Action 3 - what is to be done with that understanding? If nothing then there is no outcome!!!"* The point here, is that unless something substantial and significant takes place then nothing is likely to change. Equally, participants also commented that there were many well-meaning 'Actions', and they couldn't see: *"what was going to happen as a result?"*

Participants offered suggestions which they felt could be achieved to demonstrate that their voices were being heard. In no particular order, they were:

1. Greater work with local community groups to gather information to arrive at positives changes which will educate and improve lifestyle;
2. Training and awareness raising - better customer care and culturally appropriate considerations;
3. GPs to spend more time with patients;
4. Better information and sharing outlets within the community and schools – to educate against misinformation through social media;
5. Health hubs in the community;
6. Mental health and early help support space for young people;
7. Fair and equitable treatment of black staff would improve perception.

In the final analysis, what sense is made of the voices will depend on so many other variables coalescing at the right moment to bring about the sort of changes that is needed. That is, variables that are unknown at this moment in time, but once they are aligned, it is more likely that change will happen. Until then, it is hoped that some of the thoughts emerging from the consultative process might just resonate which might make a difference.

The final word of one of the participants perhaps places the challenge in the clearest perspective:

"Allow Black African and Black Caribbean people to be part of the whole process! We have enough educated people in our community who can work and talk for us [and] relay our feelings and have a better understanding of the issues. I would like to see them!"

Birmingham and Lewisham African and Caribbean Health Inequalities Review (BLACHIR)

Introduction

The Birmingham and Lewisham African and Caribbean Health Inequalities Review (BLACHIR) is a joint project between Lewisham Council and Birmingham City Council to understand and take action on long-standing health inequalities for people of Black African and Black Caribbean heritage. The BLACHIR External Advisory Board summarises well the context and background to the project:

"*Birmingham and Lewisham Public Health Divisions share a joint aspiration to address ethnic inequalities, through an increased understanding, appreciation, and engagement with Black, Asian, and Minority Ethnic (BAME) groups. This has resulted in a partnership between the two Public Health Divisions to share knowledge and resources through a collaborative review process to, initially, focus on the Black African and Black Caribbean communities, to enable a more detailed and culturally sensitive approach*"[3].

A series of consultations and desk research has been undertaken to inform the *Opportunities for Action* framework (Walsall Report, 2020[4]; Children and young people's Report, 2021[5]; BLACHIR Working Group, 2020[6]). A key aspect of the overall approach has been consultation at the community level, testing out the emerging Actions as well as understanding some of the lived experiences of residents set against the emergent themes from the literature and academic conclusions.

The overarching BLACHIR Review took a thematic approach which explored specific topics to evidence needs and to recommend actions that should drive sustainable change. The themes have been clustered around eight areas as indicated below, which informed the context for the conversations so as to better understand whether those themes resonated with local people:

1) Structural racism and discrimination
2) Pregnancy and early years (0 to five years of age)
3) Childhood and being a young person (ages five to 25 years of age)

[3] The Birmingham and Lewisham African and Caribbean Health Inequalities Review (BLACHIR): External Advisory Board, July 2020
[4] Walsall Healthcare NHS Trust (2020), *'Evidence Summary Report – Birmingham and Lewisham African Caribbean Health Inequalities Review (BLACHIR)'*, Walsall Healthcare NHS Trust
[5] Bullock, M (2021), '*What is the impact of health inequalities on Black African and Black Caribbean children and young people in the UK? A literature review and rapid analysis*', Lewisham Council Public Health
[6] The BLACHIR Working Group (2020), *'Racism and discrimination in health inequalities: literature review'*, Report to the BLACHIR Advisory Board.

4) Staying healthy as you age (from 40 years of age and onwards)
5) Mental health and wellbeing
6) Habits/behaviours that influence your health
7) Social and economic influences (e.g. education, housing, employment, crime)
8) Access to health care and managing health conditions

Within the Lewisham context the engagement process was commissioned by Lewisham Council's Director of Public Health as part of a wider consultation process within the Black African and Caribbean communities led by a collaborative of Lewisham based Black third sector organisations, under the guidance of Kinaraa CIC. The approach was to focus on ensuring the lived experiences and voices of Lewisham's Black African and Caribbean communities was heard. Putting this into context, the Lewisham Health and Wellbeing Strategy states: *"Health inequalities are unfair and avoidable differences in health and wellbeing. Within Lewisham, and nationally, we know that people of Black African and Caribbean heritage suffer from health inequalities and this work aims to address them to make life fair."* It is against this background that this consultation report is to be read and understood.

However, it is important to get a better understanding of the Lewisham context that has prompted the need to explore health inequalities as it relates to Black African and Caribbean residents living in the borough.

The Lewisham context

The starting part in understanding the health profile of Lewisham is captured in the Joint Strategic Needs Analysis (JSNA)[7] reports (Part A and Part B), that was conducted in 2019, prior to the Covid-19 pandemic. This therefore mean that the impact of COVID-19 would not have been captured or factored into the analysis. That said, there is much within the analysis that is still very pertinent, which the pandemic has highlighted, such as the implication of obesity, respiratory conditions and diabetes, to name a few immediate concerns to emerge as strong underlining factors that could lead to serious health and/or death if the virus is contracted.

Diagrammatically, as Fig 1 shows, the purpose and definition of the JSNA is clear, pointing to a process of analysis of needs leading to the setting of priorities. The analysis is not solely dependent on academic research but also engagement at the local level with residents amongst other localised granular driven data and information from a range of sources (e.g. housing, policing, education and so on). From this approach the picture we have of Lewisham offers the following key insights pertinent to this review and consultation process:

Lewisham is a borough of 303, 500 and is the 14th largest borough in London by population size and the 6th largest in Inner London;

The population of Lewisham shows:

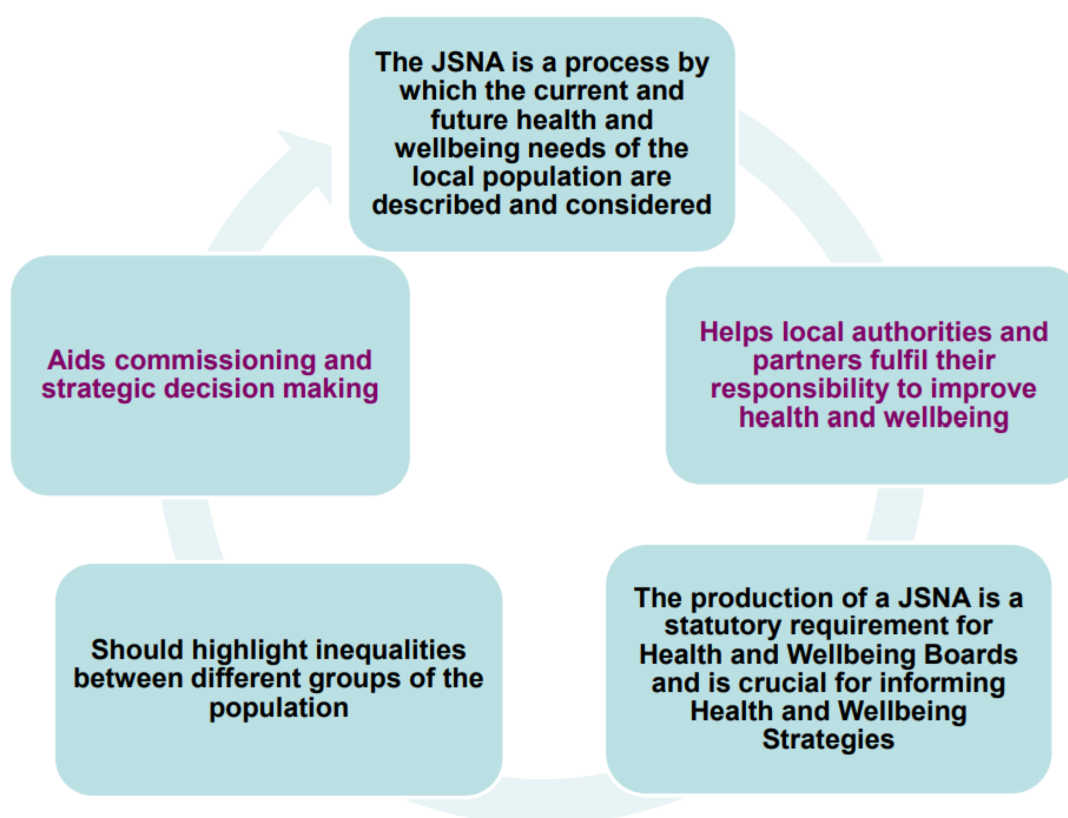
- 23% are aged 0 -17yrs

[7] Joint Strategic Needs Assessment (JSNA): Picture of Lewisham 2019 (Part A and Part B)

- 68% are aged 18 -64yrs
- 9% aged 65yrs+

The population is set to have grown following the 2021 Census to reach close to 320,000 and climbing to over 340,000 by the time of the 2031 Census. The growth will continue to follow the pattern of a younger population bias at the north of the borough (i.e. Brockley, Evelyn, New Cross and Telegraph Hill) with growth not evenly distributed across the borough. For example, Lewisham Central Ward is predicted to see notable increases due to planned developments in the area (i.e. Blackheath, Ladywell, Lee Green and Lewisham Central).

Fig 1: What is JSNA: a definitional overview



Source: Joint Strategic Needs Assessment (JSNA) Picture of Lewisham 2019 Part A

The ethnic profile of Lewisham is forecast to change by 2050:

- By 2028 it is forecast that the White and BME population will be 50/50
- Subsequently the Black and Minority Ethnic (BME) population is predicted to exceed the White population.

An understanding of the current and future ethnic composition of the borough is important as some health conditions impact disproportionately on certain ethnic groups (e.g. diabetes).

There is also disparity by ethnicity in use of and access to some services. Between 2011 and 2031 the size of the population of BME children and young people 0-19 will grow at more than three times the rate of their White counterparts while Other White residents are

growing at a faster rate than White British or White Irish (e.g. Italian, Romanian, Spanish, Irish and Portuguese being the fastest growing non-British nationalities).

The Lewisham Health and Wellbeing Board, supported by NHS Lewisham Clinical Commissioning Group (CCG) [8], has responsibility for commissioning (planning, buying and monitoring) the majority of health and care services in Lewisham. Through their work they bring together organisations across Lewisham to share expertise and local knowledge to create better health and wellbeing for Lewisham residents. The aim is to deliver joined up and co-ordinated health and social care to all residents in the borough by working together to support *'better health, better care and stronger communities'*. In 2015, they identified the following priorities:

- Prevention and early intervention
- GP practices and primary care
- Neighbourhood community care for adults
- Enhanced care and support for adults
- Children and young people's care

A fundamental plank in the strategy for delivering the priorities included *"Improving communication and engagement with the public to promote and improve the way advice, support and care is provided."* This was later refined with the production of the refreshed Lewisham Health and Wellbeing Strategy: *'Health and Wellbeing for all Lewisham residents by 2023',* which started from the premise that the:

> *"…goal of Health and Wellbeing for All by 2023 would require us to think differently about the root causes of health inequalities. We recognised that health and wellbeing is affected by social and environmental factors as well by the choices and actions taken by individuals."*[9]

The challenges that were then identified resulted in new priorities being set around three core approaches: ***populations, communities and individuals and families***[10]. A community approach – bottom up approach – was seen as critical. This was seen as a powerful way to facilitate communities' awareness of and capability to alter the factors affecting health and wellbeing delivered through community development approaches that have been pioneered in Lewisham. Pivotal within this approach was a recognition of Lewisham's voluntary, community and faith sector acting as a '*bridge'* between services and communities, and the neighbourhood care networks emerging from the integration of health and social care that is being provided. These 'bridges' can and do provide additional resources for engaging and empowering communities to improve their own health and wellbeing.[11]

It is against this backdrop that the consultation process and engagement arrangements that has enabled us to produce this report must be seen. To view it outside these parameters is

[8] *Working together for better health, better care, and stronger communities: A summary of our joint commissioning intentions for integrated care in Lewisham 2015 to 201 (January 2015)*

[9] Lewisham health and wellbeing strategy draft refresh 2015-18
[10] Lewisham health and wellbeing strategy draft refresh 2015-18
[11] Lewisham health and wellbeing strategy draft refresh 2015-18

to miss the locus of reflection and the greatest disservice to those living in the borough who are disadvantageously impacted on from the health disparity that exists.

The structure of the report moves from general descriptions to interpretative feedback and analysis arising from the exploration of the eight themes coming out of the early phases of the BLACHIR process that began in 2020 (i.e. the Birmingham study). The report is written so as to move from the general to the specific. In Section 1 we start with a focus on the methodological approach to the engagement process, which is then followed in Section 2 with our key findings arising from both the qualitative and quantitative approaches adopted. The final two sections (Sections 3 and 4) covers a discussion on the key findings with the conclusion offering some reflections on the implications for Lewisham's Health and Wellbeing Strategy.

Section 1: Engagement approach

The research included both qualitative and quantitative approaches, through structured 1-2-1 and focus group interviews and survey questionnaire. Some basic information was captured from each approach, which provided demographic and contextual information on the key characteristics of respondents.

Three organisations were engaged in the direct delivery of the field research (1-2-1 interviews and focus groups)[12]. Through their work and engagement six (6) focus group sessions were conducted and five (5) 1-2-1 depth interviews completed.

The approach adopted sought to better understand participants experience and perception with respect to:

1. Seeking support
2. Accessing healthcare services
3. Experience in using the healthcare services
4. Possible actions to overcome barriers of access and experience

As a result of the process, including the online questionnaire survey, 33 participants engaged in the focus group sessions (28) and 1-2-1 sessions (5). Through the online survey questionnaire approach, a further 55 respondents were engaged; thus reaching 88 participants from which the report analysis is based. The online survey questionnaire asked some questions that were not asked of those who participated in the 1-2-1 interviews and the focus group sessions. For example, 1-2-1 interviews and focus group sessions did not capture data on Ward categorisation, housing/accommodation status and health theme priorities, while the online questionnaire did not ask about the employment status of respondents. Where common questions were asked they have been combined to provide an overall response analysis (e.g. age range, gender, ethnicity and post code).

Quantitative analysis was made possible from information captured from the focus group sessions held, the 1-2-1 semi-structured interviews and the from the online survey questionnaire conducted. The analysis was made the more useful as the online tool used, Survey Monkey, captured and graphically represented responses as responses came in. We used a ranking approach for the eight (8) themes against which weighted average calculations were made.[13] Weighted values were applied in reverse order; that is, the respondent's most preferred choice (which they rank as #1) has the largest weight value, and their least preferred choice (which they rank in the last position) has a weight value of 1. This allowed us to evaluate the most preferred choice using the weighted score (out of the number of actions indicated across each theme, ranging from 3 to 7). We have used this

[12] The three organisations involved were Red Ribbon Living Well, 360 LSN and Action for Community Development (AfCD). Appendix 1 provides further details on each organisation.

[13] Ranking questions calculate the average ranking for each answer choice enabling the determination of answer choice being the most preferred overall. The answer choice with the largest average weighting score/percentage rate for the particular question choice is the most preferred choice (i.e. ranked position).

data to graphically represent the responses by weighted score with the highest percentage response for the chosen option shown alongside the average weighted ranked score (e.g. 2.21 etc)

Based on the three processes indicated, Appendix 2 provides graphic summaries of the characteristics of the respondents to the online questionnaire, the 1-2-1 and focus group sessions. The key features are:

- 54% were Black African and 40% Black Caribbean
- 78% were female, 16% male and 6% non-binary
- 41% were in the age range 41 - 55yrs, 32% within the broader 56 - 64yrs age and 20% within the 25 - 40yrs age band
- 49% were employed (full/part-time) while 30% were unemployed with the rest being students and retired (21%)
- 18% of respondents lived in SE6 post code, 14% in SE13 and 10% SE8, while 10% lived in Catford and New Cross wards.

Arising from the combined process, themes were extrapolated using keyword extractive approaches based on thematic analysis of qualitative responses. From this approach, further refinement was made manually to cluster the themes where they were similar and/or part of the same concerns (e.g. accessing GPs and concerns with receptionists' behaviour/disrespect, were combined under '*Accessibility to GPs'*)[14]. Where appropriate and relevant, the voices of the respondents have been incorporated to reflect the lived experiences of participants.

Thematic analysis ensured that the identified themes are relevant to the research question, and that the themes identified are applicable to the consultation process. This method was considered appropriate given the focus of the consultation and engagement process. The findings presented in this paper are organised according to the themes identified by the BLACHIR advisory team/Board.

[14] Thematic analysis is a method of 'identifying, analyzing and reporting patterns (themes) from responses and information.

Section 2: Key Findings

In their recently published report, Kapadia, Zhang et al (2022)[15], made the point that *"ethnic inequalities in access to, experiences of, and outcomes of healthcare are longstanding problems in the NHS, and are rooted in experiences of structural, institutional and interpersonal racism."* [pp.10] Their observation lay at the heart of the BLACHIR Review, and, in particular the exploration that the consultation process sought to investigate. For decades there has been widespread concerns about the health of Black and racially minoritised people in the NHS as well as the wider healthcare services. Some of the concerns alluded to in the report reflects very much the concerns we were hearing from respondents engaged in this consultation process.

Of the eight (8) themes identified to tackle race inequalities in Birmingham and Lewisham, the top three identified as priorities by respondents to the online questionnaire (based on ranking score out of 8 – Fig 2) were:

1. Structural racism and discrimination;
2. Mental health;
3. Staying healthy as you age.

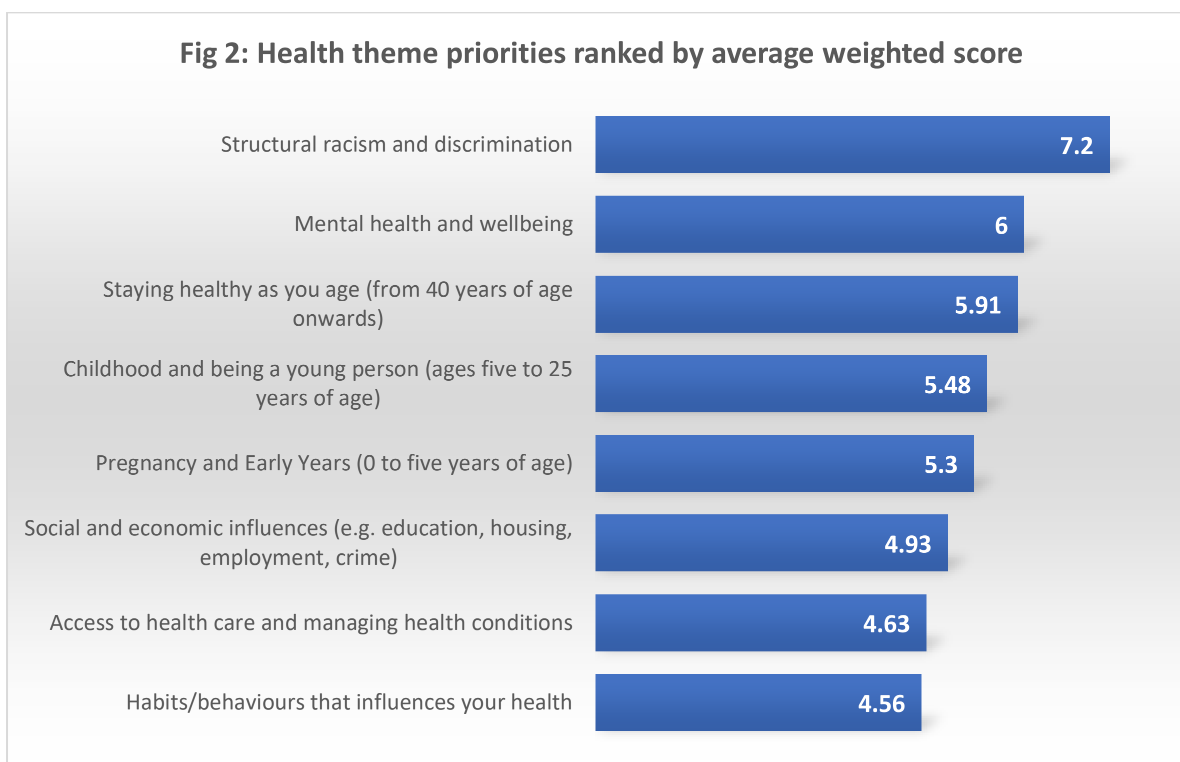
Based on feedback from the open ended questions, the focus group and 1-2-1 interviews, it is clear that African and Caribbean people living in Lewisham are concerned about the level of racism and discrimination that they perceive. Examples of comments from respondents revealed:

"As a consequence, racism has direct effects on mental, physical and social health. Effectively reducing health inequalities involves recognising and responding to the impact of racist victimisation on health: 'if we do not act to address prejudice and negative stereotyping explicitly, whatever action we take to reduce inequality…can only have partial success." [Online respondent]

"Address issues of racial profiling, stereotyping, gatekeeping, hostility and mistreatment experienced at first point of contact in GP surgeries. This negative attitude deters black people from pursuing the health care they need." [Focus group respondent]

Across each of the eight themes, respondents were asked to prioritise those key actions, drawn from the actions identified through the academic review process, that they felt would make a difference to their experience. What follows are reflections on the responses against each of the eight themes.

[15] Kapadia, D et al (2022), Ethnic Inequalities in Healthcare: A Rapid Evidence Review, Race and Health Observatory



Base n=54

Theme 1: Structural racism and discrimination

The definition commonly understood to describe 'structural racism' is that crafted by the Trade Union Congress's (TUC), which states that it is:

> *"...a collective practice that exists in workplaces and in wider society, in the form of attitudes, behaviours, actions and processes. It is the exertion of power and privilege based on race and class."*[16]

Based on this definition, respondents to the online questionnaire were offered the opportunity through the open-ended question option to provide their own feedback. From the responses, participants ranked the key actions they thought should be priorities going forward. Fig 3 shows that more people ranked *Action 2 – Recognition of racism as an adverse childhood experience*, as the most urgent action, with weighted ranking of 2.84, while Action 1 – *Removal of colour language coding in data collection,* was their second priority with weighted ranking score of 2.44.

What was most interesting was that respondents ranked Action 4 – *Council and partners need to integrate diversity into education to reflect diverse cultures* - as their third most important priority with a weighted score of 2.39. What makes this interesting is the often referenced work that is taking place around equality, diversity and inclusion (EDI) within public and private sector organisations, has become prominent and pronounced since the

[16] Hussain R, *Shining a spotlight on structural racism in Britain today*, March 2018 (Shining a spotlight on structural racism in Britain today | TUC)

Black Lives Matter (BLM) demonstrations in 2020[17], and yet from the feedback, it would seem that these are perhaps not actions and approaches seen as top priorities. This raises questions as to whether those affected negatively by the healthcare service actually recognise these overtures as being of any help/support to their day to day lived experiences. That is, they are not likely to change their lives significantly.

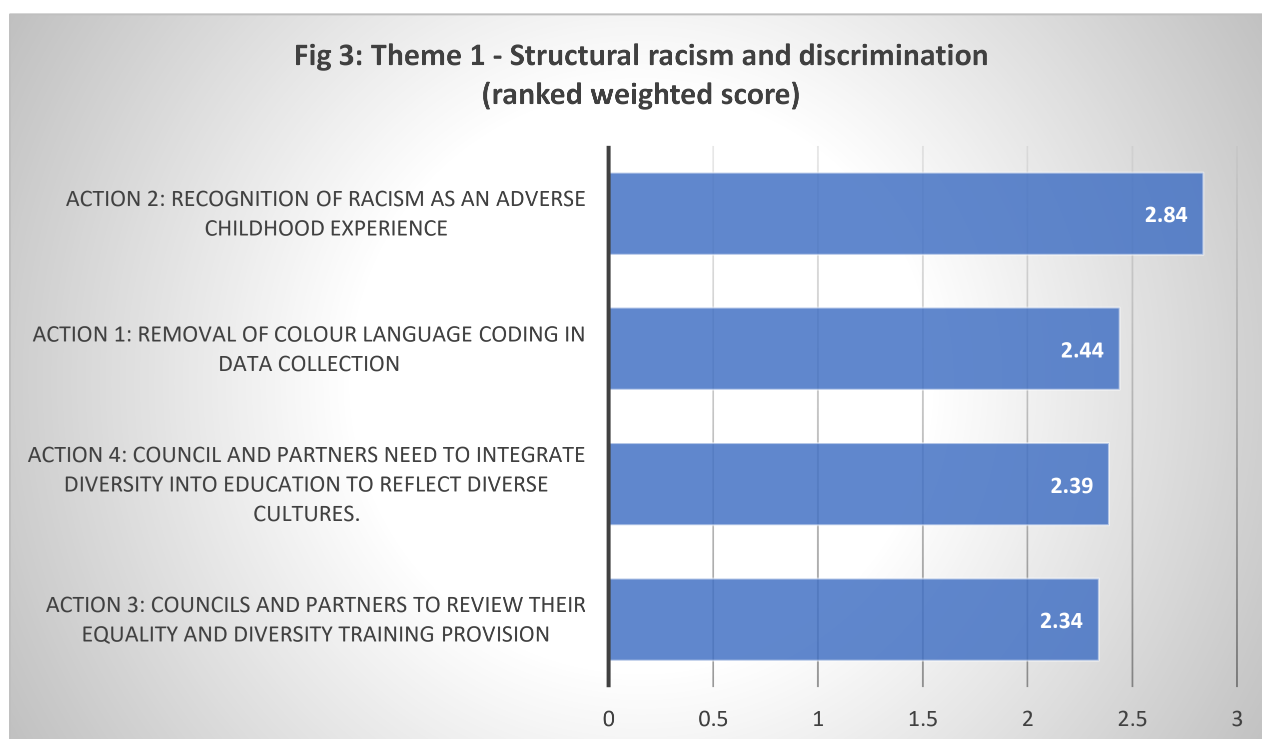
This observation was borne out through comments as:

"Stop continually reviewing, doing more studies as the evidence and studies already exists of inequalities. Develop strategic links to actions for which all will be held accountable for implementing." [Online respondent]

"Integrating black and other cultural histories within the British curriculum on a more permanent monthly basis rather than having things like black history month. Also, encouraging training programmes and management programmes for people of ethnic origins." [Online respondent]

"Teaching positive Black history and experiences in all schools. Teachers should all be trained on what racism is and how their behaviour impairs child development." [Online respondent]

"It is not only reviews, but actions and monitoring with clear accountability so as to be outcome driven. Not sure what outcome will be delivered with action 1. Inclusion is essential and those decision makers who orchestrate changes should be representative of those communities they serve. If the desired outcome is not achieved try again with fresh lens." [Online respondent]



Base n=80

[17] George Floyd was murdered by a police officer in May 2020, the outraged that followed, sparked a worldwide Black Lives Matter(BLM) campaign, the reverberation of which has had a major impact on issue of equality, diversity and inclusion right across all spheres of political, social and economic life.

Theme 2: Pregnancy and early years (0 to five years of age)[18]

Walsall Healthcare NHS Trust's published literature review explored various interlinked aspects of health inequalities relating to pregnancy, early years and parenthood specifically in Black African and Black Caribbean communities and comparisons to other ethnic groups. The evidence obtained highlighted health inequalities relating to pregnancy, early years and parenthood between different ethnic groups in the UK (Mindell, 2014, Phung, 2011 and Public Health England, 2017 and 2018) and disparities in UK BAME communities compared to other countries (Nazroo, 2018).

The evidence relating to pregnancy includes barriers for Black African and Black Caribbean women accessing prenatal, postnatal or maternity services (Chinouya, 2019 and Maternity Action, 2018), birth outcomes (Khalil, 2013 and Datta-Nemdharry, 2010 and 2012), diseases in pregnancy (Gopal, 2019) and deaths of mothers (Knight, 2018) compared to other ethnic groups.

The evidence relating to diet in early years highlights the variation of breastfeeding (Tariq, 2016 and Santorelli, 2013), weaning (Moore, 2014) and parental feeding practices (Gu, 2017 and Korani, 2018) between different BAME groups. The relationship between ethnicity and childhood obesity is explored (Falconer, 2014 and Whincup, 2015). Physical health in early years between BAME groups is examined in relation to exercise (Trigwell, 2015 and Love, 2019) and physique (Hancock, 2015).

The evidence relating to parenthood explored the lived experience of Black African and Black Caribbean fathers (Williams, 2013 and 2012 and Baldwin, 2019) with parenting roles of the extended family examined by some studies (Victor, 2019).

The stigma experiences by young black mothers looked after by the state is discussed (Mantovani, 2014) Initiatives supporting parenting programmes to support ethnic minorities (Scott, 2010 and Maynard, 2010) are highlighted. The evidence explores the attitudes of ethnic parents to the diet, weight management and physical activity of their children (Ochieng, 2011 and 2020 and Trigwell, 2014 and 2015) as well as beliefs about vaccination (Tomlinson, 2013). The cultural influences, lifestyle choices and attitudes relating to sexual health of Black African and Black Caribbean parents compared to other BAME groups are outlined (Gerver, 2011 and Ochieng, 2017).

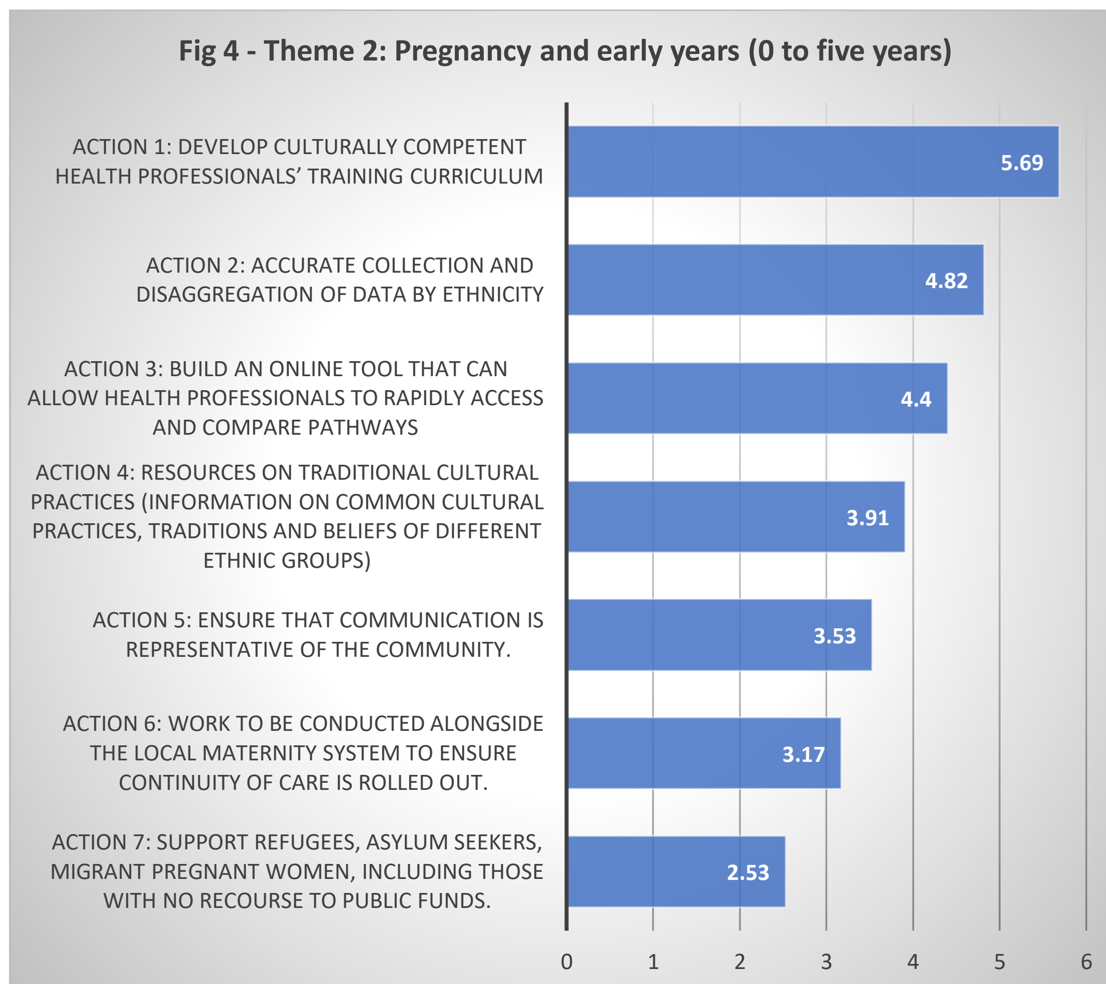
Theme 2 contained seven 'Action' imperatives that were explored with respondents, from which the top three 'Actions' identified followed the order as outlined in the Opportunities for Action plan (Fig 4):

Action 1: Develop culturally competent health professionals' training curriculum with a weighted ranking score of 5.69;

Action 2: Accurate collection and disaggregation of data by ethnicity with a weighted ranking score of 4.82;

[18] Evidence Summary Report – Birmingham Lewisham African Caribbean Health Inequalities Review (BLACHIR); November 2020 - Birmingham City Council and Lewisham Council Public Health Divisions. All references are cited in this publication.

Action 3: Build an online tool that can allow health professionals to rapidly access and compare pathways with a weighted ranking score of 4.4.



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The observations from respondents to the focus group and 1-2-1 interviews, as well as the open-ended responses, highlighted the following comments:

"Refreshed training for all healthcare professionals as a work-related reminder for treating people the way they would like to be treated. Reminding health care professionals to have a good customer service polite language like bankers." [Online respondent]

"Data is essential to prioritise those most greatly disadvantaged and marginalised. In addition, the low hanging fruits should be action following by a determined plan of action for others given the limit of resources." [Online respondent]

"White counsellors seem not interested. They're going through the motion unlike black counsellors. In my experience I was able to give back some sense of empathy. There is the ability to discuss with the personal journeys and experience it with somebody from your own background while this wasn't possible with a white worker." [Focus group respondent]

Theme 3: Childhood and being a young person (ages five to 25 years of age)

From the review undertaken by Lewisham's Public Health[19] (2021) around the health and wellbeing of children and young people, a number of themes of concerns were identified, which included:

Physical health: BMI was shown to potentially overestimate the burden of overweight and obesity in Black children because it fails to account for body composition, specifically body fat, which on average is lower in Black children, who also tend to be taller; physical activity levels were not lower in Black children, but cultural factors may affect parents' engagement with out-of-school physical activity interventions; Black children generally had lower blood pressure than White children, but Black boys showed a greater increase in blood pressure from 12 to 16 years than White boys; Type 2 Diabetes risk factors in Black children were broadly comparable with those seen in White children (South Asian children were at higher risk), but Black children in higher Socio-Economic Status (SES) groups may show more risk markers than White children of the same SES.

Mental health and emotional wellbeing: Black African and Black Caribbean children and young people generally reported higher levels of mental wellbeing than White participants of the same studies, however one study found that Black Caribbean children reported higher levels of social difficulty factors at 7 years old. Family activities and cultural integration (identified as ethnically diverse friendship circles) were shown to have a protective effect.

Risky behaviours: There was evidence of ethnic diversity in risky behaviours and in risk factors for behaviours. White and mixed ethnicity young people reported higher levels of substance misuse than Black young people, and Black Caribbean young people were most likely to report having unprotected sexual intercourse; Black African young people generally had fewer risky behaviours than Black Caribbean young people; cannabis use, mental health difficulties and strong peer or neighbourhood affiliation were associated with risky behaviours; a seven year study in a London GUM clinic found that Black British and mixed ethnicity teenagers were over-represented in the cohort of teenage pregnancies, compared to the study setting's clinic population.

Educational attainment: Black African and Black Caribbean children, on average, reported higher levels of aspiration than White children in multiple domains, including school, yet Black Caribbean pupils on average have lower levels of academic attainment; school factors included the recognition and celebration of cultural diversity and of Black cultural identities within the school setting.

Social inclusion: Black young people in contact with Youth Offending Services may not have equitable access to healthcare, with mental health needs in particular less likely to be identified and supported; young Black men's early exposure to 'adult' styles of policing may create feelings of unsafety and social exclusion; Black children were, on-average over-represented, in the care system; engagement with a variety of health services may be lower

[19] Bullock, M (2021): *What is the impact of health inequalities on Black African and Black Caribbean children and young people in the UK? A literature review and rapid analysis*; London Borough of Lewisham.

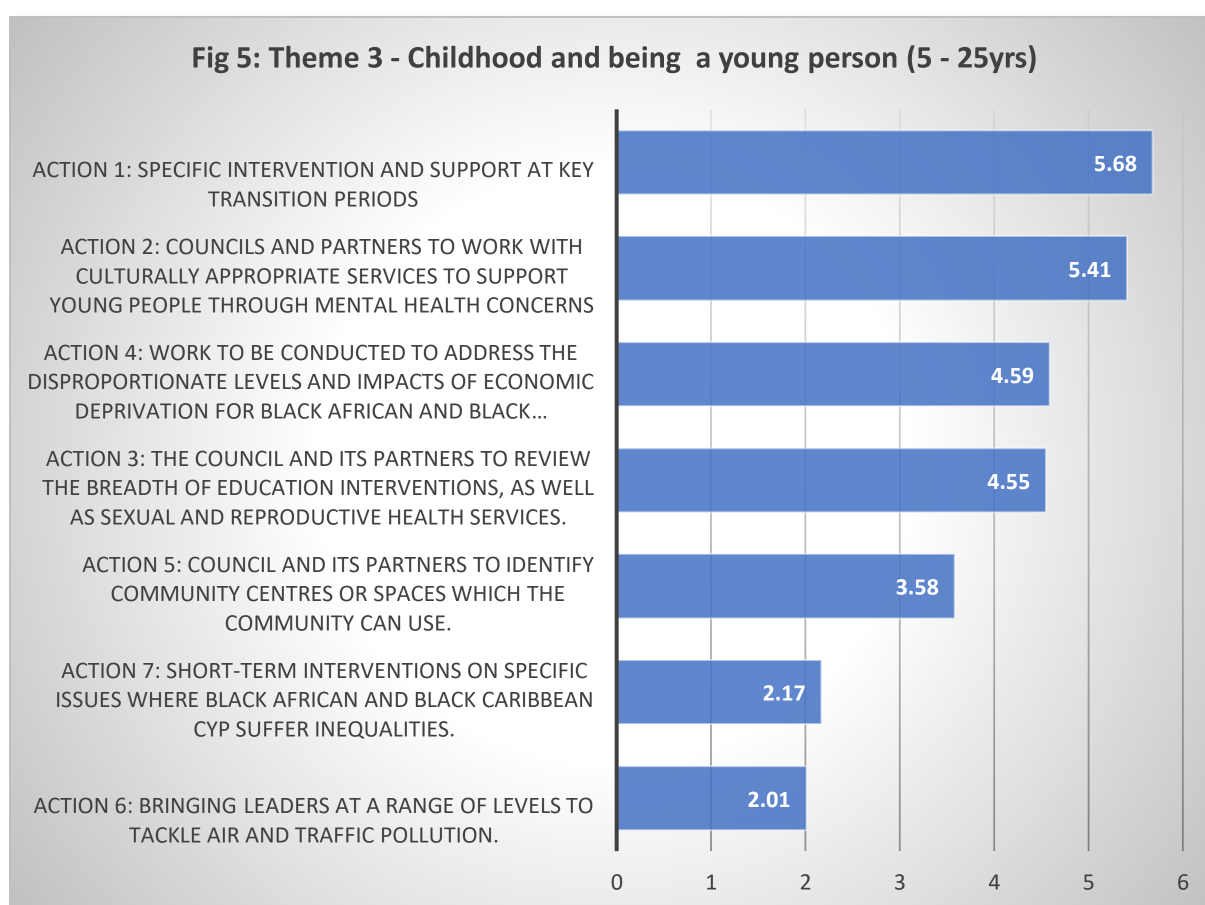
in Black African and Black Caribbean populations, including immunisation, CAMHS, and being registered with a dentist.

Theme 3 contained seven 'Action' imperatives that were explored with respondents, from which the top three 'Actions' identified were (Fig 5):

Action 1: Specific intervention and support at key transition periods with a weighted ranking score of 5.68;

Action 2: Councils and partners to work with culturally appropriate services to support young people through mental health concerns with a weighted ranking score of 5.41;

Action 4: Work to be conducted to address the disproportionate levels and impacts of economic deprivation for Black African and Black Caribbean communities with a weighted ranking score of 4.59.



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Comments captured from respondents on their lived experiences reflected the general tenets of the findings, which reinforced the priorities identified:

"Understand the poor health experiences of black people and ensure equal access to therapies rather than being medicated." [Online respondent]

"Medium and longer term interventions to support black communities that suffer inequalities and robust sanctions when this happens to demonstrate the Council's commitment to eradicating racism and discrimination. Investment in communities developing services as they know best what they need." [Online respondent]

"Focusing on youth employment creating jobs within 16 to 25-year-olds support for mental health housing food clothing etc; fatherhood programmes when men could support each other as also support the local wider community." [Online respondent]

"Ensuring the curriculum pushed in schools isn't glorifying racist authors or texts such as Roahl Dahl, Of Mice and Men etc." [Online respondent]

"Parents to make sure that they know friend of their children and to engage young people with house activities like cleaning, cooking, washing clothes and ironing, washing up dishes, etc making sure that they are being used at home rather than depending on the outsiders like group etc. Charity begins at home. It's parent's responsibility to teach their children discipline and how to behave and respect." [Online respondent]

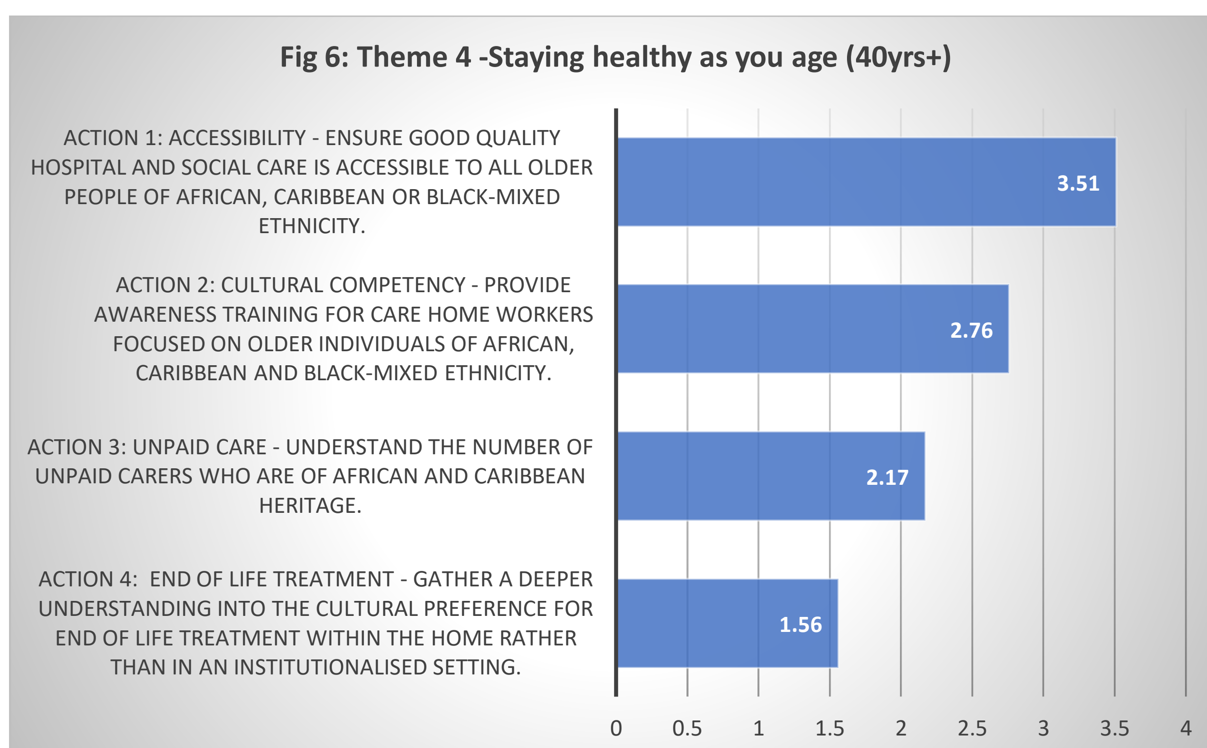
Theme 4: Staying healthy as you age (from 40 years of age and onwards)

Theme 4 contained four 'Action' imperatives that were explored with respondents, from which the top three 'Actions' identified followed the order as defined in the Opportunities for Action plan (Fig 6):

Action 1: Accessibility – ensure good quality hospital and social care is accessible to all older people of African and Caribbean or Black-mixed ethnicity, with a weighted ranking score of 3.51;

Action 2: Cultural competency – provide awareness training for care home workers focused on older individuals of African, Caribbean or Black-mixed ethnicity, with a weighted ranking score of 2.76;

Action 3: Unpaid care – understand the number of unpaid carers who are of African and Caribbean heritage, with a weighted ranking score of 2.17.



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From the comments and discussions that took place, it was very evident that participants were concerned about how the elderly was being treated and/or accessing the healthcare services. They included:

"Racism training compulsory for all professionals and robustly monitored with the involvement of service users." [Online respondent]

"Patient voice captured and incorporated in service improvement. Tailored relevant health information that supports good health." [Online respondent]

"Financial and respite support for carers within the community will be an advantage moving forward." [Online respondent]

"Action 3- what is to be done with that understanding? If nothing then there is no outcome!!!" [Online respondent]

"Immediate racism training to be completed by LA System Leaders." [online respondent]

"The elders have to queue up, they struggle and are not mobile savvy. It has become frustrating. The more able-bodied person can access at least three devices so they can make arrangements using mobile devices and it can take up to 45 minutes waiting to get through to somebody for an appointment. These are some of the issues that the elder generations face." [Focus group respondent]

"I needed surgery and I've been affected by mobility and having to live in pain with pain." [Focus group respondent]

"Since December 2021 I have been waiting to see a physio and I'm in pain. They tell me someone will get back to me but so far no one has. That is what we are often told." [Focus group respondent]

Accessing GP services was of particular concern and came up in all the focus groups:

"…getting to them via the online takes forever to get an appointment; almost 2 weeks. The GP services need to be more available." [Focus group respondent]

"You ring from early hours, and you still don't get an appointment. We need allocation of time." [Focus group respondent]

"We are limited to what you can discuss with the doctor in that you can only talk about three things in 10 minutes. You get cut off and then next appointment I will follow up." [Focus group respondent]

"I couldn't get any joy with my doctor in Lewisham, so I changed to one in Croydon." [Focus group respondent]

A disability participant commented: *"… I have been ringing since October 2020 and no response as yet as to an appointment. I finally got a response in May 2021 but still no one got back to me up to now [Feb 2022]."* [Focus group respondent]

Theme 5: Mental health and wellbeing

Theme 5 contained three 'Action' imperatives that were explored with respondents, from which the 'Actions' identified were in the same order as presented (see Fig 7). The responses were closely clustered, which suggests the differences between the actions were fairly small.

Comments from respondents indicate some confusion about the choices while at the same time endorsing some of the action points indicated:

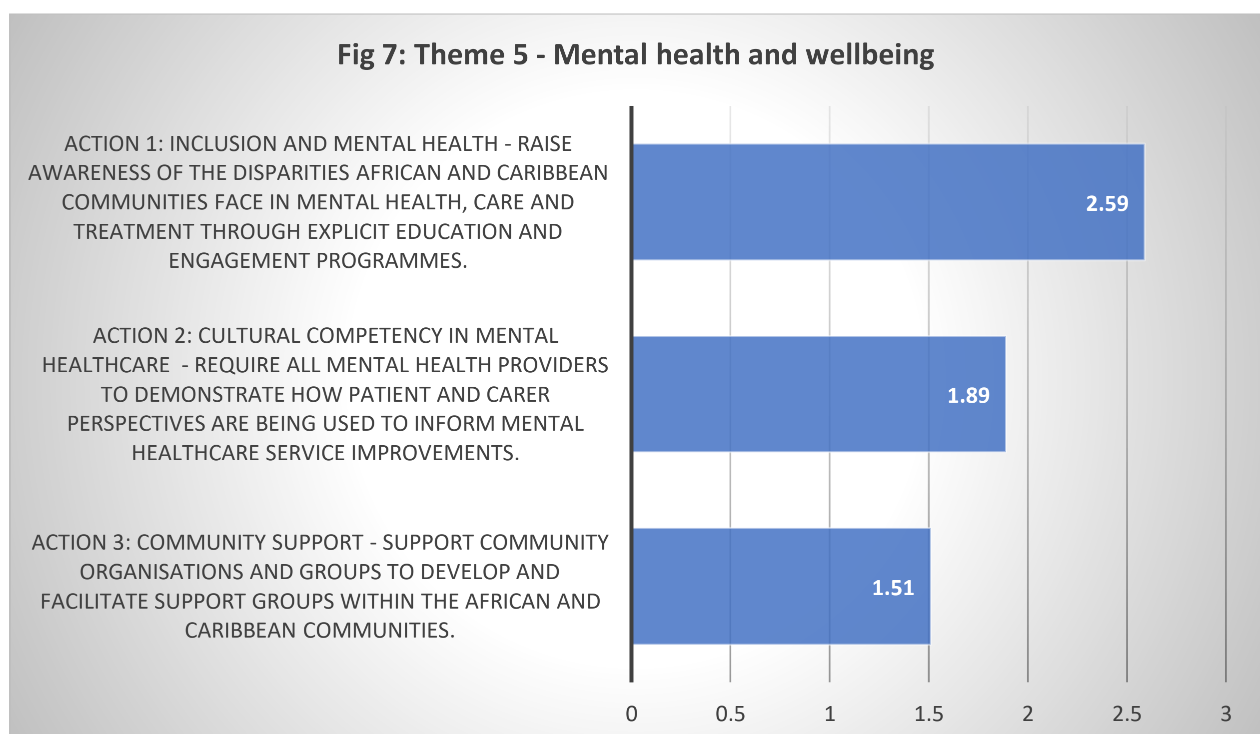
"All professionals undergo racism training and service users involved in ensuring policy and practice is adhered to." [Online respondent]

"Neuro diversity is an area that have to be explored company called neuro pool I recommend highly as they look at the abilities of neuro diverse people rather than disabilities and how to integrate them into the community as an outfit and that includes sustainable employment training and education and learning and development for further information please don't hesitate to contact me ….." [Online respondent]

"Little unclear of the outcome of action 1? Inclusion is critical but confused by narrative above. What is done once educated? Accountability is key for action 2. For action 3 clear monitoring with outcome focus is required for meaningful outcomes. To include sharing of best practice." [Online respondent]

"Creation of Community Centre healthy active group. Healthy nutritional campaign scheme and health awareness day. Healthy eating surveillance group." [Online respondent]

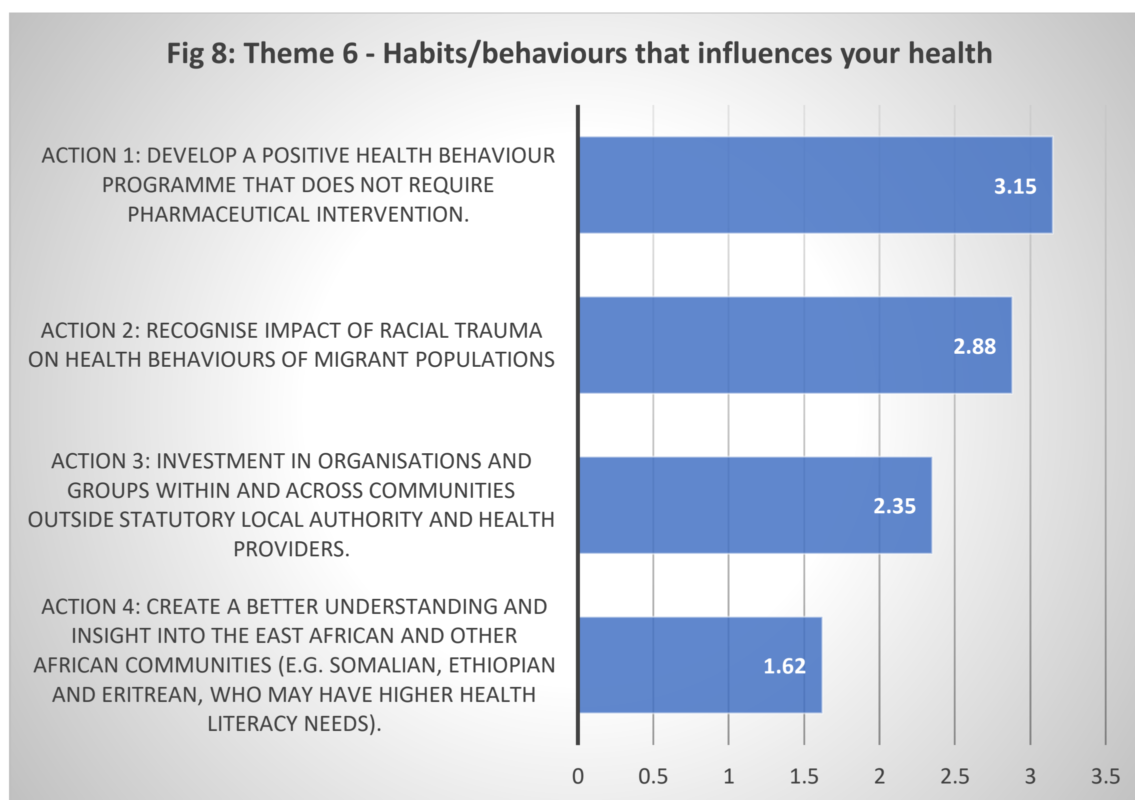
Healthcare professionals, they don't understand the black African culture backgrounds including personal life, taboos especially when it comes to mental health.



Base n =76

Theme 6: Habits/behaviours that influence your health

Theme 6 contained four 'Action' imperatives that were explored with respondents, from which the 'Actions' identified were in the same order as presented (see Fig 8). The responses to Action 1 had provoked some concerns within the focus group sessions, with participants across three of the six sessions raising this as a concern. Respondents, in the main, felt that GPs and the medical profession was too quick to 'prescribe medication' without offering them alternative options. This was especially more so from those more familiar with remedies from their country of birth: *"I would have liked to hear more about some of those remedies"* they said. [Focus group respondent]



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Comments from respondents provided a good spread of views, especially around the question of alternative medicines. Comments included:

"Regular sessions delivered in safe spaces to communities on all health conditions."[Focus group respondent]

"Funding is a basic necessity to mobilise some of the ideas coming for the actions to be practically implemented." [Online respondent]

"For Action 3 proper support is key to success." [Online respondent]

"Recognise that the solution isn't always found in drugs. We are different in our physiology thus need to work to different tolerances. Example, black men must be tested 5 years earlier than white men for prostate cancer. Testing of black men should start at 40 years." [Focus group respondent]

"I am diagnosed with a high blood pressure, and I have tried African remedies but the support group I found to be helpful. By sharing information food nutritional approaches et

cetera and referrals through connections has been made possible." [Focus group respondent]

"I've been diagnosed with depression and thought was a family issue but found it difficult to come to terms. I didn't take tablets because people said it would put and put on weight, so I don't. Work is also impacted on having difficulty with sleeping etc." [Focus group respondent]

"Those with no recourse to public funds are affected and the ability to get medication. Support groups want passport and then the NRPF have very little support. I have a strong faith which is kept and kept me straight." [Focus group respondent]

"We're going mad if i take the medication; took it and I'm not feeling well and therefore assuming the tablet/medication worsening my condition." [Focus group respondent]

"There is also the need to raise concern options in relation to alternative medicine especially natural remedies these should be more available and should be discuss more openly." [Focus group respondent]

"*Where I have had mental health suicidal tendency there is no number I can call and not everybody can call for help. Mental health patients get little support. My religion and faith prevent me from taking my life by committing suicide*." [Focus group respondent]

"There is a need to investigate whether alternative medicines do indeed have helpful properties. Drugs are poison. Good healthcare system must be put in place." [Focus group respondent]

"Traditional remedies work, something we've been used to. Back home we are used to natural herbs from the ground and now we are faced with a system that is dependent on pharmaceutical drugs. There is therefore a clash of culture." [Focus group respondent]

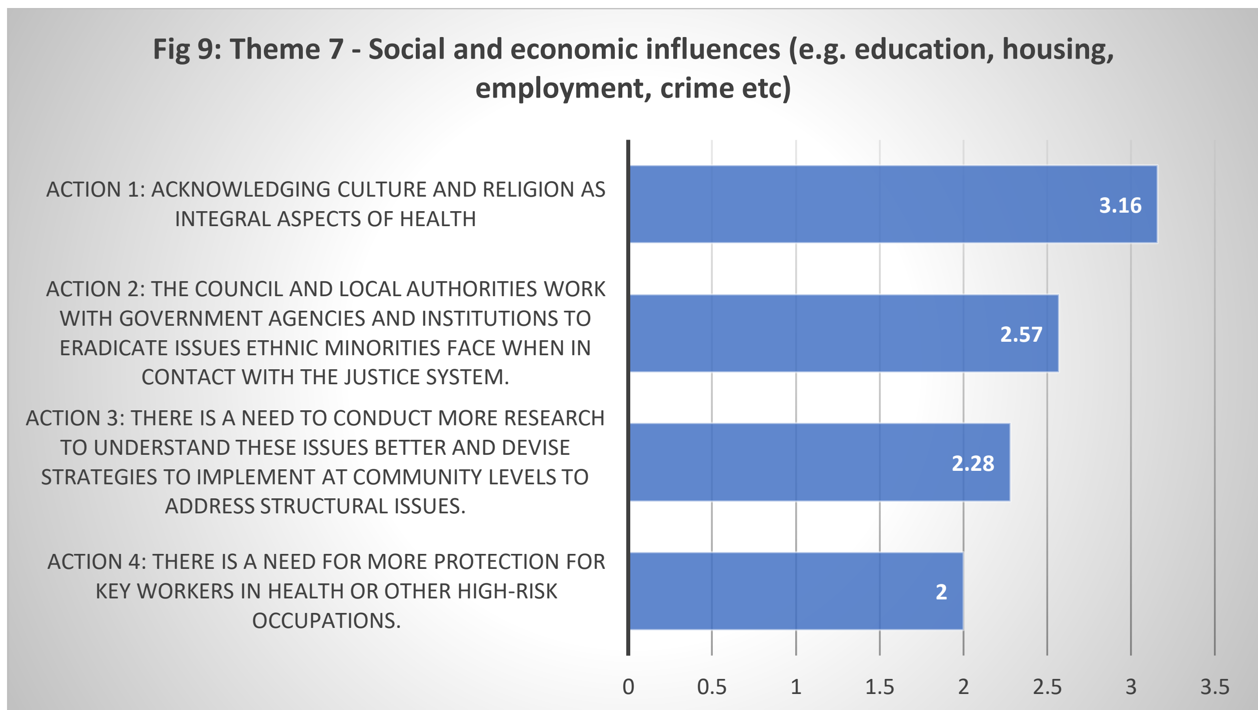
Theme 7: Social and economic influences (e.g. education, housing, employment, crime)

Theme 7 contained four 'Action' imperatives that were explored with respondents, from which the priority 'Actions' identified were in the same order as presented (see Fig 9). As the overall top ranking score was 3.16, suggesting that this was an overwhelming priority for those who responded to this. The inability to understand cultural background, including religion, was seen as a factor in them receiving good health care. This was a point some respondents commented on, with some participants concerned about how the actions would be realised.

The JSNA (2019) report concluded that crime has a number of impacts on health, including fear of crime and the direct impact of detrimental effect on the physical and mental health of victims. Thus:

- Lewisham has the 17th highest crime rate in London (MPS, 2017/18)
- Hospital admissions for violence are now in-line with the London and England average (HES, 2015/16-2017/18)

- 26.6% of offenders are recorded as re-offending, in-line with London and England (2014, MoJ)
- The police are involved in a number of initiatives and groups alongside the council and health partners such as the Alcohol Delivery Group.



Base n= 76

Reflecting on their own experiences, respondents offered insights which shed some further light on some of the challenges in accessing good healthcare in Lewisham as well as possible shortcomings in actualising the actions. Some respondents were mindful that some of the healthcare issues related to issues such as poor housing conditions, crime and traffic and road work related congestions. They stated:

"…the wider social conditions are factors, such as housing, education criminal justice system. These are some of the challenges that also triggers mental health." [Focus group respondent]

"I live in cramped conditions and have to share rooms with different sexes. We have to remove and relocate to other accommodation, but I have to ask other councils as Lewisham doesn't have any units big enough for our needs." [Focus group respondent]

"…. without being action outcome driven, we could end up with reports and data with little difference being made. Those with decision making power should include the communities served and be held accountable on an on-going basis. We are starting from a low base and there is much to do. Allies will be important in pushing for the changes we want to see. However, those changes should be informed by our experience, and we should have representatives from our community to speak out at the decision making table." [Online respondent]

"Performance reporting should be published more readily and openly for communities to access." [Focus group respondent]

"There are other issues to contend with such as housing, financial, immigration and poverty. These compound the situation and make our health worse; this adds to our mental health." [Focus group respondents]

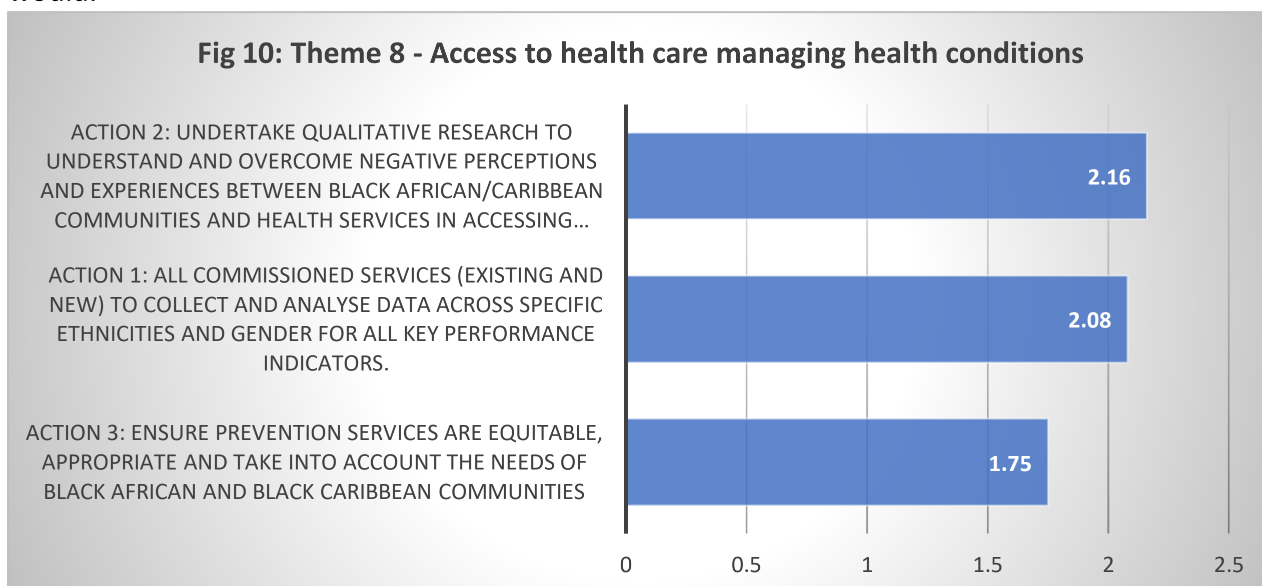
"We are not seeing people because there is a lack of networking due to Covid and the restrictions. This is affecting relationships. People are not eating well largely due to financial insecurity leading to unhealthy eating; we need therapeutic options, exercises and be able to see appropriate and relevant people." [Focus group respondent]

"*Ongoing leaks, can't get through to the repairs line; I am getting no response to online reporting - weeks later still nothing. I live in a high rise flat with people always sitting in the stairwell on the ground floor. It's not a good condition."* [Focus group respondent]

"… racism is an issue because of police and their reaction to black boys. Stop and search is everywhere which has led to crime." [Focus group respondents]

Theme 8: Access to health care and managing health conditions

Theme 8 (Fig 10) contained three 'Action' imperatives that were explored with respondents, from which the top priority was Action 2 – *undertake qualitative research to understand and overcome negative perceptions and experiences between Black African/Caribbean communities and health services in accessing care, including the influence of structural racism and discrimination* (weighted average ranking score of 2.16). What is of interest is that respondents felt that Action 1, which referred to the collection of data, was recorded as being of second top priority of the three Actions indicated. This, linked to Themes 1 and 2 on data capture and Themes 5, 6 and 7 to wider understanding of the impact and effect of health inequalities, suggest that Black African and Caribbean communities are not averse to engage and share their experiences. It is of interest because it is often said that Black African and Caribbean people do not want to (or indeed) engage in consultation processes. The overall responses to this process would suggest otherwise and the responses to questions of further 'qualitative' research and engagement would seem to suggest that they would.



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Generally, the comments from respondents reflected a sense of willingness to engage as well as indication that their voices are not being heard, especially where long term health care is concerned. Comments indicated below provide a useful summary of the tenor of the voices coming through:

"I'm a firm believer that intervention is better than cure so preventative pressures." [Focus group respondent]

"All 3 are essential. Clear accountability with action for change arising and not an exercise of data collection." [Online respondent]

"Disabled black African and Caribbean people should be provided services and support they require as they tend to be left behind." [Focus group respondent]

"Regardless of ethnicity, gender etc, as far as I'm concerned, we're all family and that we have a responsibility to put positive energy into our communities to keep this world a safer place. I aspire for utopia where we are one and support each other, where everyone has the right for warmth, food, shelter, water, education etc. I'm a romantic at heart, I will always aspire to greatness." [Focus group respondent]

"Routine collation of patient feedback should be compulsory in performance reporting." [Focus group respondent]

"Long-term care you get for the older generation is poor let alone if you have HIV?" [Focus group respondent]

"We do need a care agency that is dedicated to those living with HIV+ to be put in place; we don't see much of these around." [Focus group respondents]

"An HIV plus patient went to the hospital at 7 am in the morning until 5 pm in the evening and during this waiting time nobody came out to say sorry to him instead he was told that it was on the elderly people." [Focus group respondent]

"There are no guidelines or a proper procedure for people living with HIV, especially those housebound they have to administer their HIV medication themselves. There is no long-term physical support for people living with HIV because they are aging." [Focus group respondent]

Section 3: Discussion

One of the questions posed to participants in the focus group sessions was: *'What does it mean to live in Lewisham in terms of conditions affecting health?'* This question provoked so many reactions in terms of the impact some living condition was having on people's health and wellbeing. Not only this, but individuals were very animated in their condemnation on their attempts to secure redress, especially to concerns about getting access to GPs and other health care services. Participants offered a range of situations that they felt impacted on poor health, from housing to waiting time to get through to a GP to roadworks and congestions to crime. As the recent report by Race and Health Observatory (RHO) states: "*there is a lack of appropriate treatment for health problems by the NHS; poor quality or discriminatory treatment from healthcare staff; a lack of high quality ethnic monitoring data recorded in NHS systems; lack of appropriate interpreting services for people who do not speak English confidently and delays in, or avoidance of, seeking help for health problems due to fear of racist treatment from NHS healthcare professionals."* (Kapadia,2022)

The voices of those participants that took part in our consultation process reaffirmed many of the concerns being expressed in that report. Indeed, using a thematic approach to clustering the main concerns emerging from the conversations, we have been able to identify six themes, which seem to reflect and add further weight to the ranked Actions they were asked to prioritise. In general, we found that participants' concerns and experiences fell into the following six broad and embracing areas of concerns:

1. *Accessibility to GPs (i.e. waiting time, booking appointments etc)*
2. *Trusted and accurate information (including communication and language issues)*
3. *Immigration status*
4. *Cultural expectations (i.e cultural insensitivity; taboos and stigma etc)*
5. *Care home v 'home care' concerns*
6. *Wider social and economic factors (ie. Impact of poor housing, traffic congestion and crime)*

<u>Accessibility to GPs (i.e. waiting time, booking appointments etc)</u>

Participants were particularly concerned about the difficulty being faced with trying to book appointments. Those who were elderly were seen as being more vulnerable due to their inability to access and become familiar with the technology of mobile phones, laptops and other smart devices, which they now needed to be able to get in touch with their GP surgery.

Other concerns raised in respect of trying to access GPs involved what seemed to them to be a hurdle of the 'gate-keeper'. That is, the receptionists were seen as a barrier alongside the time they can spend with the doctor, when they do eventually see them. As one respondent explained:

"….the first thing you're told by your doctor is that you a medication. We need at least three visits before we get a proper diagnosis. We are almost never believed." [Focus group

respondent]. For this patient, the doctors do not wish to engage them about their illness because they 'don't have the time'.

Another respondent highlighted how long she had to take to get an appointment. Said the respondent: *" I was really ill and couldn't get access for 45 minutes waiting for someone to see me. And when I got to see my GP he said he could only talk about one issue."* Another explained that they had a respiratory problem and her doctor just *"prescribed paracetamol which turned out to be the wrong presumption and prescription as this made me worse. I was allergic and it made me worse. I had no confidence from that moment. I cannot trust them to do anything and refuse to go back to the GP."*

On the question of the gate-keeper receptionist, respondents commented that many of them are insensitive and disrespectful. One respondent offered the following:

"There is a lack of understanding with the receptionist. They are the gate-keepers into the GP and this is difficult and I end up getting depressed."

Another commented that the *"receptionist always wants to know why you want to see the doctor. This often feel intimidating." While another respond with an example exclaiming "receptionists* need to be more responsive and respectful."

And finally, this respondent's comments perhaps sum it up well when he said:

"Difficult to get appointment to see your GP due to long waiting on calls and when calls are answered, the appointment has already gone and then you are told by the receptionist to call again the next day."

Trusted and accurate information (including communication and language issues)

For many of the participants who took part in the focus group and 1-2-1 interviews a common refrain was the lack of 'proper and accurate information' coupled with difficulties around language. As one respondent explained:

"… I have been in this country for over six years, and I have still yet to fully understand how to access information. Information is fragmented with many challenges because, in Africa, we are not used to having regular check-ups. We are now finding new diseases through this process." [Focus group respondent]

More worrying is the role social media seem to be playing in both 'diagnosis' and in obtaining information as to where to go/what to do. This example from a participant was typical of the concerns being expressed: *"Social media has become the 'source' for information and not necessarily good information ('misinformation')."* For this individual – and from the response of the others in the group, it was one that was widely recognised. There seemed to be a lack in confidence to 'challenge' GPs and healthcare professionals where feel they are not being given sufficient information and so revert to online chatter and information – some of which may not be accurate.

Where English wasn't the first language some participants felt they were at a disadvantage. Some expressed concern that they weren't taken seriously, and especially 'gate-keepers', were seeming not able to 'understand them'. These two responses make the point clearly:

"…Where English is not my first language, especially as an adult, making arrangements with others is difficult. Staff on the front line are not supportive. We have to go to A&E and wait in the line and that waiting time is very high because the GP is inaccessible." [Focus group respondent]

"People are unable to express themselves therefore they are vulnerable and when you get to see the GP they suddenly come out with: "so many of your people from your country come here with HIV". [Focus group respondent]

Immigration status

It was clear that those who are still trying to resolve their immigration status have a particularly hard time. Until their status is confirmed, it they are unable to register to a GP surgery and can only access A&E, which can clog up the system with conditions/concerns that perhaps a GP could have been able to deal with. This therefore must place extra burden on the NHS more generally, as many of those caught in this limbo state, may also decide not to access even the A&E until the condition becomes unbearable. As one respondent remarked*, "prevention is better than cure."*

One respondent offered the following insight: "People who are not in the system are not able to access medical services and immigration takes long to be decided." As they see it, those who find themselves in this situation could so easily slip through the net and could, later down the road when the condition requires surgery or worse, they become additional burden on the system. As she stated: *"…undocumented people slip through the system with "many dying for fear of being reported".* And under those situations, they do not present themselves until it's too late (or not at all). If they do not have a confirmed status they are deemed to have no legal rights and *"therefore we are not registered with a GP service."*

Cultural expectations (i.e cultural insensitivity; taboos and stigma etc)

There is a need, said participants, for there to be better understanding of the cultural needs of individuals. The views that were expressed indicated that the health care service professionals "treat all black people as the same; not all Black people are the same and we are different." The concern here is that by understanding the different cultural concerns and expectations will provide for a better service to the Black communities more generally.

As one participant puts it, *"religious and cultural expectations are different around certain things, like, for instance, requests for gender specific attention/consideration: "take all black people to be the same."* Another responded by saying that health care professionals are too *"…quick to label black children as mentally disturbed*", with *"many ending up with the wrong diagnosis and put in inappropriate places."* [Focus group respondent]

This raises questions around the need for culturally specific mental health care service provision, especially as the idea of mental ill health can be seen as a taboo matter, carrying with it a stigma. It was felt that the social prescribing approach could be an area of support, especially working with and through community based organisations. In some communities,

as participants generally acknowledged, there are certain health related concerns that are not spoken about/mentioned, even with health professionals. Issues around mental health, disability and HIV were given as examples. One respondent made the following observation:

“We need awareness raising within the community as well as in the health care services generally. Stigma around HIV and issues within hospitals and amongst healthcare professionals need to be addressed. Stigma and discrimination for people living with HIV is still there. It continues to be a problem.” [Focus group respondent]

And another retorted “[mental health] is taboo. We're told to shush, to hide and then to get help is even more difficult.” There is a thinking that this might be spiritual which mean greater awareness is needed. Another participant felt that within the African community, more so than Caribbean communities, that there is much talk and consideration given over to spiritual considerations and therefore more needs to be done to try and redress concerns around mental health. This would seem to be a concern that is levelled at the wider health care service as well as within communities.

If people with long-term conditions are treated in this way and this is Europe with expectation that it will be much better then what hope is there? Said one responded. They didn't want to touch any anything including the bedlinen they felt the user i.e. the person with HIV positive was useless and they had to and they were wearing gloves.

Care home v ‘home care concerns

Discussions around the impact and implication for the care of the elderly threw up concerns about the lack of care many believed care homes provided compared to ‘home care’ options. *Participants felt that some of care homes were not habitable nor conducive to the care their loved ones required. Also, it was stated that care homes are another ‘taboo’ subject within communities. “We need positive mindset of those who are caring in these Institutions,”* said one respondent. Overwhelmingly, the views expressed were very clear that *“care homes are uncaring and prefer end of life being at home”.* Another responded saying: “*they are not getting the care they deserve. The dignity and support are not there, while there is greater accessibility and support in the home environment.”* One respondent exclaimed that it is a ‘common knowledge *“that once you go in you don't come out."*

At another level, we heard from participants about the impact of Covid-19 on the mental state of elderly loved ones. Concerns were expressed about the isolation many were experiencing and the absence of “social clubs as they are important in offering a space in the community for gathering.” They went on to explain that many have closed down due to lack of funding and as such, what used to provide a welcoming space was no longer there: “*Programmes that enable them to get out and interact, provide some mobility and subsidised physio was no longer available.”*

Wider social and economic factors (ie. Impact of poor housing, traffic congestion and crime)

Poor housing, traffic congestion and crime in the borough was seen as factors contributing to poor health and wellbeing, especially with regards to anxiety and raised stress levels.

The conditions of some homes were said to be in poor condition, especially those living in council housing, with repairs taking some time to rectify. We heard from participants living in cramped conditions and mould circumstances. For example, one participant shared that they are experiencing a situation where repairs need to be undertaken and the landlord is 'absent' and cannot be contacted has left them feeling really anxious and depressed. Another commented on their experience with their housing association not taking their 'mould' concerns seriously. As she said, *"I have to wash the walls on regular basis in order to stay healthy. The water running down the walls, but nothing has been done I have caught a cold as a result. What regulations exist to protect tenants?"*

Crime was said to be a borough-wide concern which was affecting young people's mental state and how they relate to each other. An example from a young person of a situation shared puts this concern into perspective:

"A boy was stabbed from my school and a girl got pushed into main road on to oncoming traffic. There is increased bullying and violence in schools, and I am reluctant to go out because I don't feel safe."

Another comment makes the point that in some areas, there are deep concerns:

"In Sydenham, there were stabbings, shootings and this has made me feel unsafe on the road. We used to be able to play out freely. The council need to provide something positive instead of thinking crime is the answer there is another side of life. The stabbing of a young boy by her mother is an example of how bad things have got. You can't feel safe living in Lewisham."

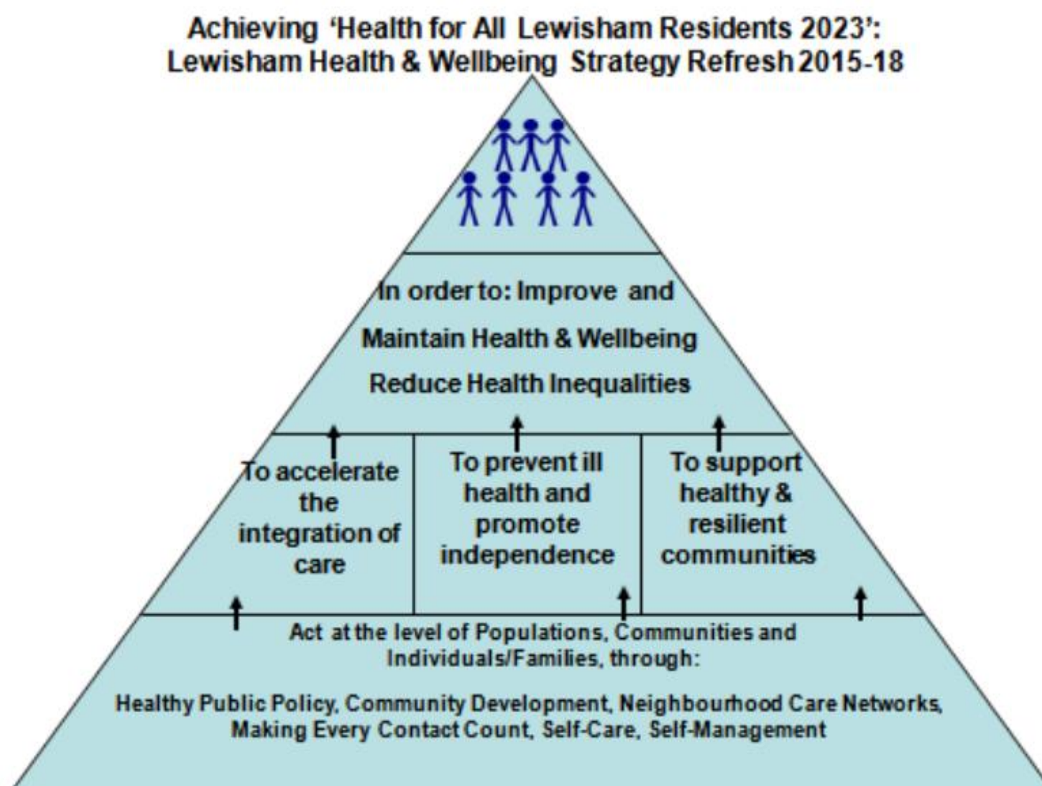
The general view was that it is not safe in the borough with people feeling scared and unsafe, even though from their own admission, *"it's not worse but bad enough."* Stabbing and violence definitely make the area unsafe, and this is affecting some young people from going out and leaving their home. In one way, this also plays in the hand of those who perpetrate violence in that the 'streets' then becomes their playground with those not involved in that type of activities staying away.

The traffic congestion is also another factor affecting poor health. This was especially seen as a result of a new diversion traffic system that was introduced in response to the pandemic but is causing much concern. This particular system saw traffic diverted in to Catford High Road. An individual in the group expressed her concern about the level of air pollution, after spending some time in the countryside for a break. When they got back to Catford they noticed the difference in the air conditions. She said it was very noticeable.

Section 4: Conclusion

The Lewisham Health and Wellbeing Strategy, as indicated in the introduction, proposes to take action at three levels: *population, community and individual/family level.* Fig 11 below presents in a simple diagrammatic form the principles and direction of travel in meeting the objectives enshrined within the priorities.

Fig 11: Achieving 'Health for All': an overview



Source: Lewisham health and wellbeing strategy draft refresh 2015-18

The 'community development' approaches alluded to, epitomised through this consultation process, sought to better understand some of the lived experiences as well as opening up vistas as to possibilities. In using the BLACHIR framework, it is evident from the previous Section (i.e. Discussion), that participants engaged through the process were able to identify some of the key challenges for them, and which reflected some of the concerns identified in the JSNA, which provide the backdrop to the Health and Wellbeing Strategy. Many of the voices that were heard, therefore, reinforced much of what is already known and therefore points towards consistency with the strategic approach advocated. For example, to reiterate the six core challenges and considerations, in the further roll out of the strategy we were hearing voices specifically focused around the following broad areas of concerns:

1. *Accessibility to GPs (i.e. waiting time, booking appointments etc)*
2. *Trusted and accurate information (including communication and language issues)*
3. *Immigration status*
4. *Cultural expectations (i.e cultural insensitivity; taboos and stigma etc)*
5. *Care home v 'home care' concerns*

6. *Wider social and economic factors (ie. Impact of poor housing, traffic congestion and crime)*

Additionally, there was a strong view that the ‘community bridges’, seen as the roles that voluntary and community organisations could play, was critical in the roll out process, especially as they represent folks who are the recipient of services. It was noticeable that throughout the focus group conversations that participants wanted services ‘closer on the ground’ to them, to have service practitioners able to identify culturally with their needs and to see good quality care services in place. The key here was not segregated provisions but good quality equitable services, especially services being offered to those who were elderly, those living with a disability and those living with long term diseases and condition such as HIV. All of these concerns were raised by the JSNA and incorporated within the Health and Wellbeing Strategy. Far from being antagonistic, the reflected voices from the participation pool of close on 90 respondents, indicated very much a consistency in identifying key actions that should be prioritised.

What sort of changes would you like to see?

In many ways, and perhaps not too surprisingly, participants on the whole indicated that any changes envisaged need to be ones that improved local resident situation and not just ‘tick box’ exercises and platitudes. As one person wrote in responding to the questionnaire on Theme 4: *“Action 3 - what is to be done with that understanding? If nothing then there is no outcome!!!”* The point here is that unless something substantial and significant takes place then nothing is likely to change. Equally, participants also commented that there were many well-meaning ‘Actions’, and they couldn’t see: *“what was going to happen as a result?”*

However, they offered some suggestions that they felt could be achieved to demonstrate that their voice was making a difference (or at least considered). In no particular order, linked to the Themes and Actions, they suggested:

1. Greater work with local community groups to gather information to arrive at positives changes which will educate and improve lifestyle (Theme 5)
2. Training and awareness raising - better customer care and culturally appropriate considerations (Theme 2)
3. GPs to spend more time with patients (Theme 8)
4. Better information and sharing outlets within the community and schools – to educate against misinformation through social media (Theme 3)
5. Health hubs in the community (Theme 3)
6. Mental health and early help support space for young people (Theme 4)
7. Fair and equitable treatment of black staff would improve perception (Theme 8)

In the final analysis, what sense is made of the voices will depend on so many other variables coalescing at the right moment to bring about the sort of changes that is needed. That is, variables that are unknown at this moment in time, but once they are aligned, it is more likely that change will happen. Until then, it is hoped that some of the thoughts emerging from the consultative process might just resonate which might make a difference.

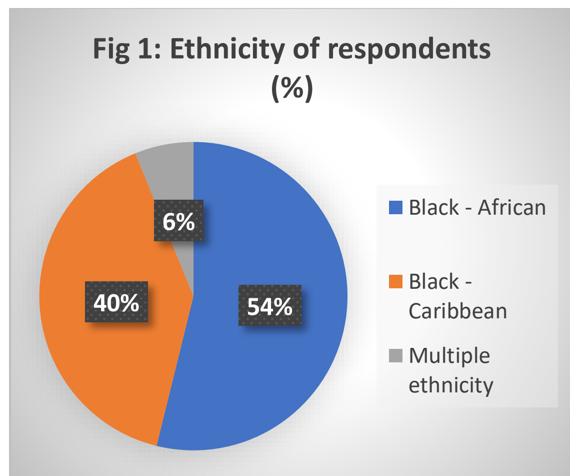
The final word of one of the participants perhaps places the challenge in the clearest perspective:

"Allow Black African and Black Caribbean people to be part of the whole process! We have enough educated people in our community who can work and talk for us [and] relay our feelings and have a better understanding of the issues. I would like to see them!"

Appendix 1: Participant characteristics

The consultation process included the capture of some key demographic information that were common across the three approaches adopted: ethnicity, gender, age, economic status, housing situation, post code and ward. Based on the responses, the following graphic summaries provide an overview of the demographic profile of the respondents.

Ethnicity



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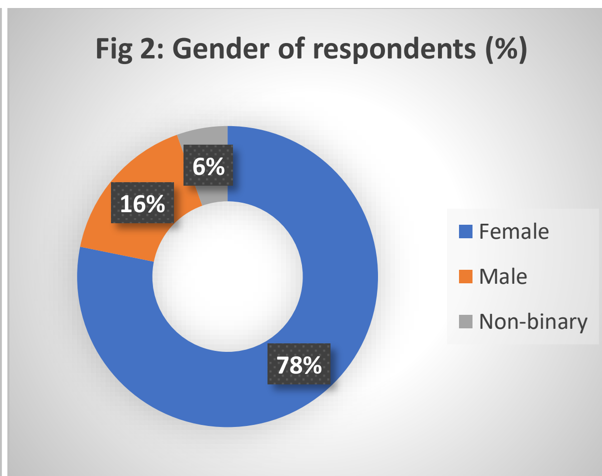

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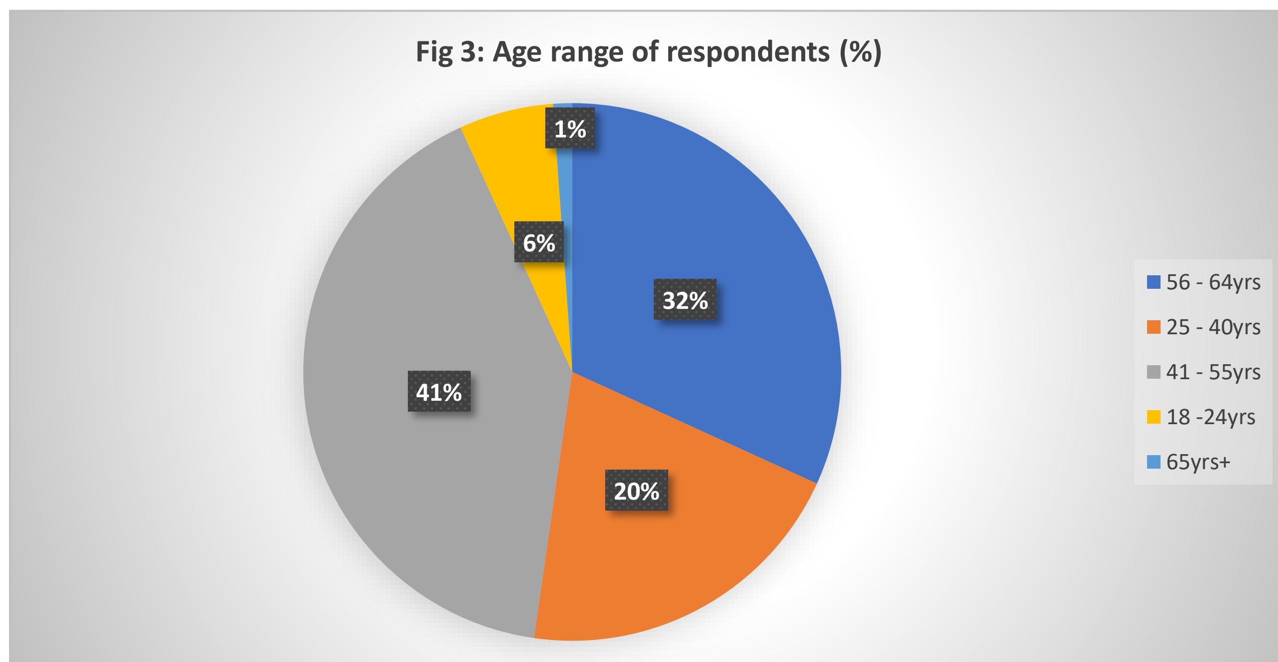

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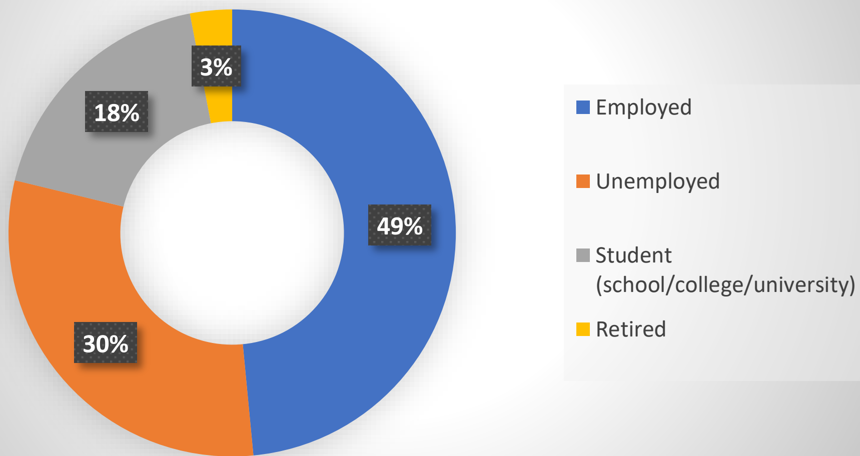

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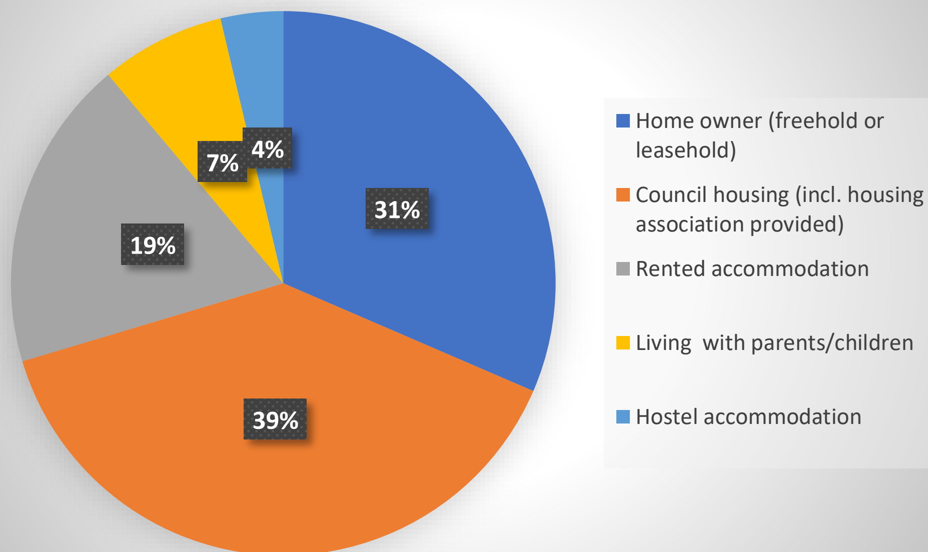

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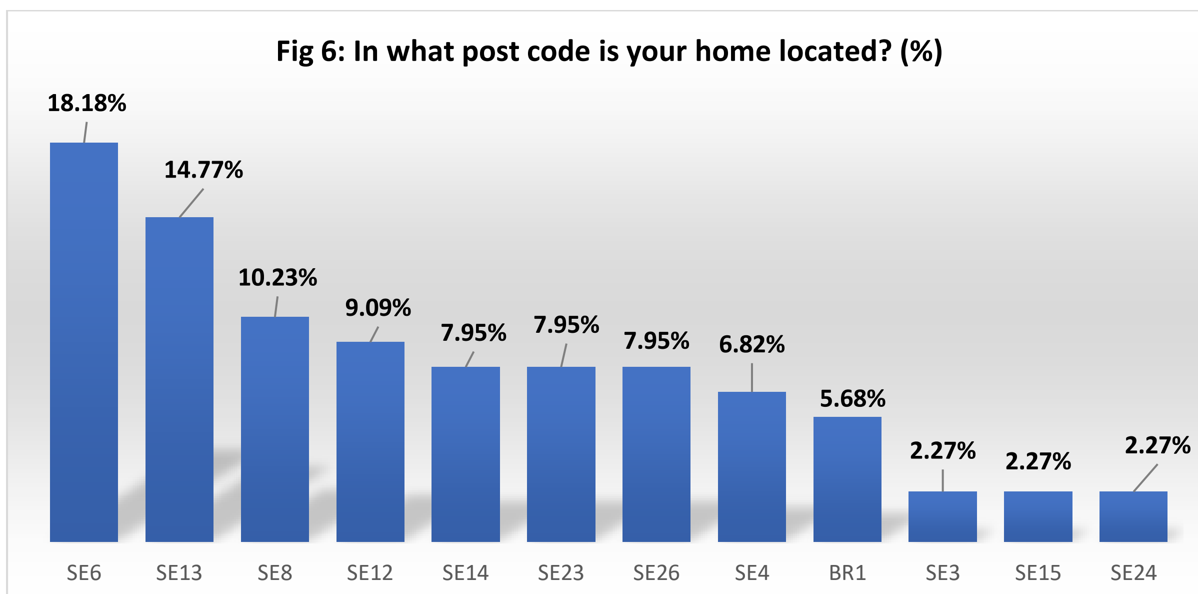

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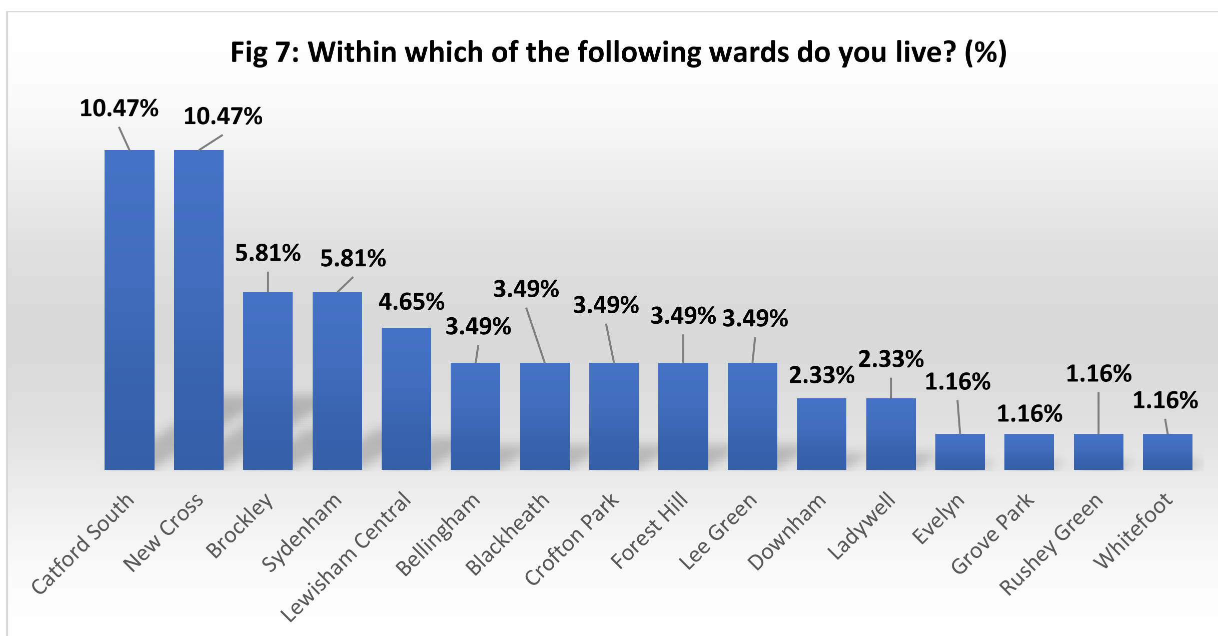

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Appendix 2: Overview of the organisations involved on the project

Action for Community Development

Action for Community Development (AfCD) is a community-based organisation assisting socially excluded members of the community such as ethnic minorities, refugees and asylum seekers and unemployed people in general. We give impartial, reliable and professional training, information, career advice and guidance.

AfCD was established to respond to reports that Refugees and people from the Black, Asian and Minority Ethnic (BAME) communities feel alienated from sources of advice, advocacy, training and statutory agencies provisions. There remain challenges to improve engagement and increased social inclusion. National statistics suggest that issues of inequality persist between different communities in British society and in many societies.

AfCD was set out to reduce these barriers, bringing about socio-economic justice and promote equal opportunities for the benefit of the wider community. We manage a resource centre in South London which offers comprehensive services to our beneficiaries. These are in the form of advice, information, casework, advocacy, counselling and training.

Our team of dedicated staff and volunteers reaches out to our beneficiaries who recently migrated to the United Kingdom and those already settled in the UK on a low income, disadvantaged or deprived. We support the transition from dependency to sustainable living. Our team consists of people with vast experience who have passion and enthusiasm for their work.

We also work with partners organisations and agencies to pool together expertise, maximise available resources to support our beneficiaries towards their goal of resettlement, skills acquisition, education and gainful employment.

Contact: ray Black and Joseph Oladuso:
Website: Home - Action For Community Development (actionforcd.org)

360 Lifestyle Support Network CIC

360° Lifestyle Support Network CIC was set up in 2021 by brother and sister duo Leon Thomson and Francine Daley. The 360 community aims to make healthcare more accessible for Black African / Black Caribbean individuals. We do this by sharing resources and knowledge regarding holistic health and wellness from industry professionals, to compliment advice of mainstream healthcare you may receive from your GP.

We educate and inspire people to change their lifestyle to create better versions of themselves. Although looking at all aspects of health, our niche focusses on topics such as Diabetes, Obesity, Hypertension, Stress and Mental Health as these are issues proven to affect the Black community the most.

We offer regular, weekly workshops in which you can expand your knowledge and ask your burning questions to a variety of guest speakers. The professionals we involve in our community come from backgrounds in health and fitness, holistic health, nutrition,

education, therapy, creative practice and much more! We focus on a new topic every week to keep things fresh.

Contact: Leon Thompson and Francine Daley: director@360lsn.co.uk
Website: www.360lsn.co.uk

Red Ribbon Living Well

Red Ribbon is a volunteer-led community organisation which operates in South East London. The group was founded in 2009 by members who recognised a need for peer support in the community, and it has grown from its grass-roots beginnings

Main Objectives:
Promoting HIV awareness and other related issues
Empower individuals affected and living with HIV to lead healthy lives
Educate members of the public around issues which have a direct impact on people living with HIV

Purpose of Project / Funding
Majority of our members are from the diaspora community and have been disproportionately affected by COVID. This has created anxiety, fear, trauma and isolation within the community.

Red Ribbon looked at providing culturally appropriate services and practical information that resonate with our members through virtual spaces. We aim to raise awareness about COVID, providing information in simplified language, understood by our members and sharing their experiences about the impact of COVID on their lives.

Funded Project Activities with Africa Advocacy Foundation.
Online focus group discussions which involved sharing experiences around the impact of COVID-19 (i.e. emotional lifestyle, situation, news or information, effects of lockdown etc).

The project provided a safe space, both virtually and physically, to engage, ask questions, and seek emotional and practical support by analyzing coping mechanisms for its members who suffered with mental health, isolation, loneliness, financial burdens and poverty.

The project also collaborate and work in partnership with the Phoenix Fund, Deptford People's Heritage Museum, Goldsmiths Department of Visual Cultures, Lyla's Place, Counselling with a Creative Touch, Lewisham council, Brook (Love Sex Life).

Contact: Husseina Hamza and Rose Euprase
Website: Home | Mysite (redribbonlivingwell.org)

Kinaraa CiC

KINARAA was born out of 6 Black led organisations working together during the COVID 19 lockdown spring & summer 2020 delivering a variety of culturally designed of services. That work was showcased at a national ageing summit and nominated for the Lewisham Mayor's Award 2021 for the programme and volunteering.

KINARAA CIC, an infrastructure support organisation, provides the right services for the development of a vibrant, effective, sustainable, and influential Black and Minority Ethnic led third sector and community organisations in Lewisham, and collaborates to offer services beyond its borough boundary.

This independent organisation has representation from the Lewisham BME Network, established by the Stephen Lawrence Charitable Trust, with over 50 local BAME third sector organisations and groups with expertise ranging from long established training providers, leading artists and heritage expertise, through to faith-based specialist organisations and informal social groups.

Contact: Barbara Gray

Website: Kinaraa | A Diverse Local Market of Service Providers

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- Fund raising and securing investments through commissioning and grants opportunities.
- Interim management
- Monitoring and evaluation
- Training, programme, staff development and performance management (independent investigations)
- Research and reviews

Contact: Karl Murray; **info@fwbusinessltd.com**

Website: FW Business Limited (fwbusinessltd.com)