



EXPERIENCES OF ACCESSING HEALTH CARE SERVICES IN MANCHESTER

BLACK & OTHER MINORITY ETHNIC GROUPS

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FOREWORD

BHA for Equality has been commissioned by Manchester Health & Care Commissioning to carry out patient surveys since 2012. Gathering evidence of patient experience is an effective way of assessing the quality of NHS services and from this recent engagement exercise it is increasingly clear that it provides a very useful insight and assessment of good practice and areas for improvement.

Over the past 27 years, BHA has delivered a range of services covering health promotion and support. In relation to our HIV prevention programmes it is disheartening to read the examples of the way in which individuals living with the condition are treated by staff in the NHS. Major developments have been made in the treatment of HIV and people are living longer with the condition and the trialing of Pre-exposure prophylaxis (or PrEP) offers people, at very high risk of HIV, medicines to lower their chance of getting infected. Just as progress has been made in medical treatment, progress is required in the provision of good quality care and support services provided by NHS staff.

The report raises many pertinent issues including the provision of psychological support for sub-sets of communities in Manchester such as Asian women who have faced domestic violence and the need for GPs to understand the impact that domestic violence can have on an individual's mental health. Health providers in Manchester have acknowledged the need to increase access to IAPT but this needs to be supported by social prescribing to enable certain groups to develop their self-confidence and rebuild their lives as well as a better understanding by some GPs.

If patients are unhappy with the way in which they have been treated they have the right to complaint. However it is apparent from the findings of this report that, although patients have a good understanding of the complaints process there is still a lack of confidence in the system. This may be reflected in the low numbers of complaints, from individuals from a BME group, which are recorded by PALS.

Year on year BHA has been able to get more people to participate in our patient experience survey and we will continue to work with the public sector to increase and improve patient participation.

I take this opportunity to thank Donna Miller, Associate Director for Policy & Development for managing the project and the researcher, Ashok Patnaik, who led on the survey design and fieldwork.

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Pakistani Resource Centre - Men's Group
Wai Yin
Women's Voices

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We also thank the practice managers and other members of staff at the 13 GP surgeries who took the time to promote our survey in different ways and for enabling us to visit their premises to talk to patients. We are equally grateful to the patients for offering their time to share their experiences to enable us to produce such a comprehensive report.

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SECTION 1 – INTRODUCTION

1.1 Background

BHA for Equality in Health and Social Care (BHA) is a charity which exists to improve health and social care equality and to support Black and Minority Ethnic (BME), marginalised and disadvantaged individuals, families and communities to improve their health and wellbeing. BHA offers a range of community health promotion / education programmes on long term conditions that disproportionately affect BME groups such as HIV, cancers, Hepatitis C, tuberculosis, stroke, diabetes, coronary heart disease and sickle cell/Thalassemia.

BHA's Manchester Race & Health Service was commissioned by the Manchester Health & Care Commissioning (MHCC) to carry out a BME patient engagement project. This work involved gathering the views of BME patients, members of the public, and carers who have accessed healthcare services, over the last 12 months, which included GP surgeries, dental practices, community health services and NHS hospital Trusts.

This is the third BME patient experience survey undertaken by BHA's Race & Health Service. Previous findings have been used, alongside other evidence, to present a case to improve services, for example, improved access to and better quality interpretation services in hospitals; promoting greater awareness of the NHS complaints system; and improved access to GP appointments.

BHA's own previous surveys as well as those of the NHS indicate that BME patients tend to have lower rates of participation in patient experience activities. Therefore, there is a relative dearth of information about their experiences. BME patients also tend to report lower levels of satisfaction with healthcare services. MHCC recognises that BME groups often have different experiences of care from other groups.

1.2 Project Aims

The purpose of this project was to identify the key concerns of BME patients and their carers so that MHCC could implement measures to improve the experiences of this cohort. The information generated by this research project was intended to enable MHCC and healthcare provider organisations to re-design services to reduce the disadvantages experienced by members of BME communities in accessing healthcare. Further, individual feedback was to be given to the participating care provider organisations to assist them in understanding the perspectives of their BME patients so that their needs could be met more effectively.

In addition to the report to MHCC, the output from this research is to be submitted for publication in peer-reviewed journals and presented at a conference organised by BHA.

A secondary purpose of this project was to obtain reliable and accurate local information about the care experiences of BME communities. While a considerable amount of national-level data and research evidence exists on this subject, it is not known whether

this pattern is replicated at a local level. The aim of this engagement exercise was to develop a body of accurate local knowledge which could inform local policy-making and practice.

An important aim of this project was to give a voice to those individuals and communities who often go unheard because of multiple social disadvantages. Their relative lack of power means that their needs are sometimes given less priority than the needs of those who enjoy more privileges. Articulating the experiences and perspectives of marginalised and excluded communities and bringing them to the eyes and ears of healthcare professionals was a key aspiration of this exercise. There was an inherent advocacy role to this project, and this was expressed through the raising of formal complaints with General Practices (GPs) and NHS hospitals on behalf of patients who had unsatisfactory experiences of receiving care. This advocacy role was an important part of the impact of this project.

1.3 Methodology

This project comprised a quantitative and qualitative approach. The quantitative strand consisted of a questionnaire. The questionnaire was designed in both paper-based and online modes to elicit information on the principal areas of interest to the commissioners of this study. The qualitative strand consisted of focus group discussions (and unstructured interviews carried out as part of the questionnaire survey). These discussions and interviews were carried out to obtain more detailed data on the care experiences of people from various minority ethnic communities in Manchester. By using different methods, it was expected that a more thorough account of people's experiences would emerge.

Quantitative Strand: The questionnaire was designed by the team at BHA in consultation with potential respondents. The questionnaire built on previous surveys carried out by BHA. It incorporated questions from NHS patient experience surveys where there was an overlap in the subject of interest. New questions were added to meet MHCC's specifications and their requirements for information.

The questionnaire was designed with active patient and public involvement. It was rigorously piloted, going through multiple iterations and revisions based on the feedback received. Members of staff of BHA (including a Research Fellow) and service users of the organisation (also from a BME background), who comprised a small, albeit non-representative sample of the BME population were asked to complete the questionnaire and offer suggestions. Feedback from MHCC commissioners was also sought and used to improve the design of the questionnaire.

The project was designed in a highly collaborative way. From the design stage, emphasis was laid on ensuring accessibility, inclusiveness, and the active involvement of participants. Co-production was very much an active guiding principle in the construction of the survey.

The questionnaire was offered in both online and paper formats (see Appendix 2). The online survey was designed using the Survey Monkey platform. In order to widen the reach of the survey and maximise the response rate, the online survey was embedded on the homepages of GPs' websites. In addition, invitations were sent out by GPs to BME patients through text message (using MJOG) and email to complete the online survey. The online survey was also publicised using the social media platforms Facebook and Twitter.

Recruitment: The principal mode of recruitment of participants was through the research team visiting voluntary sector organisations, hospital sites and GP surgeries and recruiting BME patients from their waiting areas. Thirteen General Practices across North, Central and South Manchester were visited (see list of GPs below) to ensure a comprehensive Manchester-wide coverage. This was to ensure that the sample was as diverse as possible, and that people from various geographical areas, socio-economic strata and minority ethnic communities were included.

North Manchester

1. Newton Heath Health Centre
2. Parkview Medical Centre
3. Simpson Medical Practice
4. New Islington Medical Practice

Central Manchester

5. Longsight Medical Practice
6. Rusholme Health Centre (The Robert Darbishire Practice)
7. The Arch Medical Practice
8. Chorlton Family Practice
9. Parkside Medical Centre
10. Ashcroft Surgery

South Manchester

11. Kingsway Medical Practice
12. David Medical Centre
13. Woodlands Medical Practice

The implementation of the survey at GP surgeries was one strand within a wider strategy of engagement. In addition, two NHS hospital sites (the Diabetes and the Rheumatology clinics at the Manchester University NHS Hospital Foundation Trust) were visited to engage with users of secondary care services. The survey was also publicised through voluntary sector organisations and local support groups for those with various long-term health conditions.

While BHA had engaged with other voluntary sector organisations in the past, this was the first time it had engaged with primary and secondary care providers. Therefore, the scope and reach of this project was wider than in previous practice.

The BHA research team worked collaboratively with the primary care development teams of MHCC and practice managers to recruit participants to the project. In order to persuade GPs to participate in the project, presentations were made at locality meetings of Practice Managers across the city. BHA researchers also liaised with the Equality and Diversity Manager and Patient Experience Manager at the Manchester University NHS Foundation Trust, and with coordinators' at voluntary sector organisations, to obtain access to hospital clinics and service users of VCSE organisations.

Sampling was, for practical purposes, random. 573 BME patients agreed to take part, and questionnaires were administered to them. A wide range of communities were surveyed: from Black Caribbean, Black African, Mixed South and East Asian (Indian, Pakistani, and Bangladeshi), to white minority patients (Irish, European and ROMA). During the conduct of the survey, patients who wished to give verbal feedback in addition to, or instead of, completing the questionnaire were also interviewed. Some patients preferred to talk through their unsatisfactory experiences. Some of these discussions turned into impromptu unstructured interviews of patients' experiences.

While the main focus of this exercise was on the patients, in some cases, the carers who accompanied these patients to GP surgeries and hospitals also got involved in the discussions. Through these exchanges, their own experiences both as carers and patients (in their own right) came to light. For example, a homeless, drug-addicted British Indian woman talked about the difficulties in obtaining the right medication and the unsympathetic, sometimes, harsh attitude of GPs. A Czech woman and her daughter talked about an operation of the abdomen that still hadn't healed and gave the woman pain. A very elderly woman in her eighties with multiple long-term conditions of asthma and oculopharyngeal muscular dystrophy narrated her experiences of receiving poor care and not being provided essential medication at an A&E Centre.

A summary of the findings from the questionnaire is set out in Section 2.

Qualitative Strand: The qualitative strand consisted of five focus group discussions. The aim of this strand was to cover a cross section of individuals as follows:

- Particular racial groups
- Living with particular long term conditions
- Reflected different sexual orientation
- Reflected a range of age groups

Owing to insufficient time the project teams were unable to target all the above, within this strand of the work, but propose following this up in future engagement work. The questions used in the focus group discussions were designed by the project team after consultation with service users and the project manager. The racial groups with which the focus groups were carried out were: patients living with HIV of Black British/African descent; South Asian women who were survivors of domestic violence; elderly Pakistani men; a mix of middle-aged Pakistani, African and Eastern European women; and a group of elderly Chinese men and women.

Participants were recruited by approaching voluntary sector organisations that served these specific communities. The focus group discussions were arranged by tapping into scheduled social events and meetings for the service users of these organisations. BHA researchers visited these organisations and moderated the discussions.

The group size was, on average, six to eight, and the discussions lasted around an hour and a quarter. The discussion with the Chinese group was facilitated by an interpreter from the Chinese community. The discussion with the South Asian women and the Pakistani men required partial interpretation for some participants, which was done by a BHA researcher who spoke Hindi and Urdu.

The discussions were audio-recorded, and the recordings were transcribed and analysed thematically.

Supervision of Volunteers: Two volunteers contributed to the project. One was assigned to do data entry (entering the survey questionnaires online) and the other assisted in data collection at three General Practices. Other BHA staff members also supported the project by carrying out a significant amount of data entry work.

SECTION 2 - FINDINGS AND THEMES

Analysis of Questionnaire Results

2.1 Introduction

573 individuals completed the questionnaire which covered 28 questions broken into the following areas:

- Overall experience of care
- Influence of race/ethnicity on the experience of care
- Experience of provision to meet patients communication needs
- Involvement in decisions about care provision
- Awareness of ways to raise concerns or make complaints about care provision
- Experience of participating in consultation events
- Access to health information
- Awareness of the 7 day GP service

- Equality monitoring data related to individuals completing the survey as well as information about their health status and whether they had a long term health condition.

The following gives a summary of the responses of individuals to the questions but it should be noted that not all 573 participants responded to all 28 questions:

2.2 Overall Experience of Care

Overall Experience of care was identified as being good (48%) by 276 participants and very good (32%) by 182 participants. 3% of participants (17) felt their experience of care was bad and 2.2% (13) experienced very bad care. 81% (467) of participants strongly agreed that they were treated with dignity and respect by NHS staff whilst 10% (56) strongly disagreed or disagreed with this.

2.3 Influence of race/ethnicity on the experience of care

81% (458) of respondents did not believe that the quality of care that they received was influenced by their race or ethnicity but 24% (133) felt their care was influenced by NHS staff perception of their nationality, language, colour of their skin and their faith.

Examples given of the latter are as follows:

‘Sometimes I think they [NHS staff] look and treat me differently because of my ‘religion, because of my Hijab and sometimes they may think I am on benefits’.

‘Sometimes I experience racist attitudes’.

‘It mainly relates to staff being impolite.’

‘I received worst care because of my nationality’

‘Some girls in reception (GP practice) have been rude when they hear my accent. One refused to give me an appointment. Nurses have been amazing though’.

‘During a recent visit to a certain clinic, I was informed that due to my African heritage and background it put me at high risk of sexual health related diseases which I found to be condescending and derogatory at the same time considering the high levels of promiscuity in all cultures.’

‘I felt the treatment [I received] was based on negative stereotypes of a minority’.

Despite the above 62% (341) of respondents agreed or strongly agreed that NHS staff were caring and showed concern for them and their condition whilst receiving treatment as opposed to 13%(72) that disagreed/strongly disagreed.

2.4 Experience of provision to meet patients' communication needs

8% (45) of respondents identified that they had required the services of an interpreter when accessing health services and 91% (41) of those were able to get an interpreter. 62% (28) found it easy to access an interpreter and 14% (6) found it difficult.

131 respondents identified that they had additional communication needs such as requiring sign language. 59% (79) felt their additional communication needs had been met in accessing health services whilst 39% (52) felt they were not met. Limited information was provided to support the latter but the few examples included services failing to offer an interpreter, preference in assistance from family members where respondents have a speech impediment and the lack of availability of translated materials or interpreters who speak particular languages eg Russian.

2.5 Involvement in decisions about care provision

Positive responses were provided by the majority of respondents when asked about being involved in the planning of their care and being given a choice of treatment. 81% (438) of respondents indicated they were involved in the planning of their care and 72% (388) being offered a choice of treatment, if relevant to the condition. 65% (348) were informed of costs, risk and benefits of treatment options but 25% of respondents responded negatively to this question because they were not informed of differing costs of treatment options alongside benefits and risks.

2.6 Awareness of ways to raise concerns or make complaints about care provided

72% (389) of respondents knew they could make a complaint about care provided compared to 28% (149) who did not. Of the 389 people who provided additional information on the different methods of complaining many knew a complaint could be made in writing/email or in person to a senior member of staff but only 10 were aware of the PALS service, 15 knew to direct a complaint to the Practice Manager of a GP surgery, 3 referred to MHCC, 1 to Healthwatch, 3 to NHS England and 1 to the Ombudsman. In previous patient experience surveys conducted by BHA we have identified this area as one which is problematic with many people not wishing to pursue a complaint, when poor treatment has been received, or believing that it would not make any difference to quality of care in the future or in fact could make the situation worse should they have to receive further treatment.

Even though there was a lack of clarity about who a complaint could be presented to 75% (289) of respondents indicated that they would feel comfortable about making a complaint. We attempted to gather some information on the types of issues respondents had complained about but few examples were provided. We also sought to identify what would deter respondents from making a complaint and a few examples were given as follows:

- Lack of information on the complaints process

'I don't feel comfortable making a complaint'

'I've not got around to complaining. Also the doctor was a locum and not a regular at the practice so I'm not sure if the complaint will be effective and where to take it with locum doctors.'

- The length of the complaints process being off putting

'It would probably be a lengthy procedure'

'Too time consuming, the issues are endemic'

'I don't have the time for the complaint'

- Fear of future care being compromised because of a complaint

'I was concerned about how my future care might be affected which deterred me from complaining. I would welcome advice and support from an independent person about the process of lodging a complaint'.

'I hesitate because of my poor knowledge of English. Fear of retaliation'

- Lack of confidence in the complaints system

'I am not confident that my complaint will be handled unbiasedly'

'I already made a complaint but nothing happened because all are NHS staff including PALS'

2.7 Experience of participating in consultation events

Only 16% of respondents have been involved in a health consultation compared to 84% who had not. The majority of respondents indicated that they were unaware of consultations events that had been held.

2.8 Accessing health information

When asked who they would go to for health information respondents indicated the following:

GP	84%	443
Internet sources	27%	141
Hospital	26%	139
Family/Friends	25%	133
Pharmacy	19%	103
NHS 111	15%	80
Other	13%	71
NHS Choices	10%	55
Community health clinic	8%	43

It is interesting that only 15% (80) of respondents accessed the NHS 111 service and only 10% (55) refer to accessing NHS Choices in particular. There was a heavy reliance on accessing information from various internet sources. Accessing health information online was also included in responses to the 'Other' category.

2.9 NHS Health Checks

Free NHS health checks are for people aged 40-74 years of age who are not taking medication for a long term condition such as diabetes, high cholesterol or heart disease. 40% (209) of respondents were eligible for a free NHS health check but only 108 had undergone the health check. Of the remainder (101) a third indicated that they were unaware of such checks.

2.10 Awareness of the 7 day GP service

41% (216) of respondents were aware of the 7 Day GP service compared with 59% (310) who were not. 35% (76) of respondents had used the 7 day GP service.

2.11 Better Management of Long Term Conditions

40% (212) of respondents had a long term condition with the largest groups living with high blood pressure, diabetes, arthritis or asthma/other long term chest problem. Most respondents were happy with the support provided by NHS staff in managing their conditions:

'I have Hepatitis C. I'm a 27 year old girl who has lived this for 10 years. They've always helped me and reminded me that it needs treating. I am happy with the support I am receiving'.

However some participants felt further help was required in provision as follows:

Improved communication

'I feel there needs to be more communication especially when you have more than one condition and when they link. I feel you have to see different departments for everything and no one oversees this'.

'By listening to their patients and explaining the procedures beforehand and during their hospital stay. Keeping them well informed of any changes that may occurred throughout their care.'

'More understanding of my conditions. Explained rather than being printed off.'

'Greater liaison between hospital specialist and GP specific interventions'

'By listening to me and making me an equal partner in my care.'

'Would like to deal with regular GP instead of so many different people'.

Regular health reviews

'Regular checks or bi-annual reviews'.

'It would be nice if blood pressure review is provided once in a while. At least once in two months.'

'Inhalers & asthma check-ups'

'Regular check-ups at hospital and GP surgery.'

'Offer advice, a medicines plan and equipment follow up (if needed)'.

Better treatment support

'Health and care staff need to learn more about sickle cell disease so it helps them to understand the disease more'.

'Less waiting time for specialised service'.

'More advice about diet and exercise to manage my diabetes'

'Having physio and medications'.

'Advice & counselling'.

'Better mental health support & knowledge when changing medications'

'Prescribing something other than drugs'.

'Receiving physiotherapy for painful joints.'

2.2 THEMES ARISING FROM FOCUS GROUP DISCUSSIONS

Theme 1 – Confidentiality

Confidentiality, or the lack of it, was highlighted as a major issue by African patients diagnosed with HIV. Cases were reported of the inappropriate disclosure of patients' private health-related information to members of staff at hospitals who did not need access to that information. For example, one patient complained about porters at Hospital X discussing her HIV diagnosis openly and revealing it to other staff, patients and members of the public within earshot. The patient expressed surprise at how information about her HIV positive status had gone from the doctors and nurses to the porters. Patients were very unhappy about the breach of confidentiality.

Information about patients' HIV diagnosis was not only revealed inappropriately to other healthcare staff, but also to the patients' family members, sometimes with significant adverse consequences for the patient and their relatives. Patients who had not disclosed their HIV diagnosis to their children showed their grave displeasure at NHS staff discussing their health condition in front of or within hearing of their children. The discussions between NHS staff and patients, and clinicians' line of questioning, made children inquisitive about what it was that ailed their parents. This put the patients in a very difficult situation.

They had to struggle with the anxiety and insecurity of confronting the issue of their health condition with their children. In some cases, the parents' health status was revealed to their children directly by NHS staff in clear violation of their duty of confidentiality.

A participant in the research described how disturbed she felt when NHS staff referred to her HIV status indiscreetly in the presence of her children. This example illustrates the need for NHS staff to ask parents whether they have revealed their health condition to their children, and if they haven't, to offer them privacy while discussing their treatment:

Just two weeks ago, we went for a test. The thing I wasn't happy with was that when we were inside there with my children, they [NHS staff] started asking me deep things, talking openly about HIV. I was feeling so shaken because my children are young, only five and six. They don't know about my status. I didn't know when the right time to break the news to them was. I am still struggling with that. You might think that they are still small children, but, trust me, especially, my big boy, he captures things so fast, and he is so inquisitive, and so sensitive and curious. Every time they asked, 'Oh, did you breastfeed? Were you taking medication while breastfeeding?' All those things. Fortunately, my children were just trying to play (at the time) but they were with me. Even now I am still struggling. I am still feeling shaken. I am just waiting for the day when my son will ask me, 'Mum, what was all that about?' I just felt so bad about it.

The inappropriate revelation of sensitive patient information was reported to have occurred in many settings and to have been done by different healthcare professionals – by nurses talking outside wards, by midwives discussing it in maternity wards, etc. This, patients suggested, reflected an under-appreciation by NHS staff of the deep stigma associated with HIV in the African community. This lack of understanding was demonstrated, for example, by a doctor at a hospital who went to the reception area and announced a patient's name *and* her HIV status within hearing of everyone seated there. The patient took offence at her health condition being revealed needlessly in a public area by the doctor. She felt that the doctor only needed to state her name to invite her in. There was no need for the doctor to state her health condition. It was embarrassing for her to have the HIV word added to her name in public. She felt that she had been exposed publicly.

A breach of confidentiality was reported by a patient when she was being treated at Hospital X. She said that it was the worst behaviour she had experienced from a hospital and in her view, staff had violated their duty of care by making public her HIV diagnosis.

The inappropriate disclosure of their HIV diagnosis annoyed some patients resulting in them challenging NHS staff and being labelled as aggressive. The labelling and stereotyping of patients living with HIV made them feel victimized and discriminated against.

Theme 2 - Assumptions

Patients diagnosed with HIV reported feeling acutely aggrieved at being victims of misconceptions and prejudices about HIV:

'When you go to A&E, once you mention your diagnosis, everybody starts looking at you differently, which is not fair. HIV is not a killer. It won't affect you if somebody near you has got it. It is just like any other disease when handled properly. Most of them make racist remarks because they think that because we are from Africa, that is where we have got the HIV from. There are a few ignorant ones like those.'

Patients were angry about NHS staff making unwarranted and inaccurate negative assumptions about the routes of HIV transmission. Patients objected to the stereotyping of individuals with a HIV diagnosis, especially those of African origin, as having contracted the disease through sexual transmission. As one participant described it:

'Because they don't have the knowledge, they believe that we have been prostitutes. When they look at you, they just think, "That is a prostitute." I was in a coma for three weeks. I requested my medical notes for that period of my life which I had lost. My notes said that I was a prostitute. Even if you are a man, they will say that that is what you have been doing. So, that is the stigma we face.'

This participant had approached her solicitors in order to investigate a possible instance of medical error by staff at Hospital Z where she was being treated. Her solicitors requested her medical records from the hospital. In the records provided by the NHS Records Office was a statement that she was suffering from a sexually transmitted disease. She objected to this misrepresentation by the Records Office that she had contracted the HIV infection through sexual activity. A legal case is ongoing in relation to this matter.

Equally, participants of Asian origin reported feeling that they were treated differently from white patients. One participant recounted the story of her niece who is a healthcare professional and works in the NHS. She was unhappy with the care that her family had received from the NHS and felt it necessary to discard her Hijab and dress in a Western

style to attend a meeting regarding her complaint. She felt that if she wore traditional dress, her complaint wouldn't be taken seriously.

Another participant, however, agreed with the view that Asian patients are treated differently:

'I have experienced that myself. My husband's first language is not English. When he has gone and spoken to a doctor, they are just like, not really paying attention to him. But when I go, because I can speak proper English, and I know what I am saying, then they will answer the questions properly. But still I get that look because I wear a salwar-kameez.

Thus, there were divergent views on whether Asian patients were treated in a discriminatory way by NHS staff. There was also a recognition that some people from Asian communities disempower themselves by deferring too much to healthcare professionals.

Theme 3 – Lack of Emotional Support

One of the principal concerns that emerged from the group discussions centred on the lack of emotional support and empathy from healthcare professionals. This was a particularly salient issue for patients with significant mental health problems such as the female survivors of domestic violence who took part in the discussion.

Concerns were raised about the manner in which some GPs had dealt with safeguarding issues in relation to their children. The GPs' approach was described as insensitive and callous at worst and clumsy and heavy-handed at best. These women were deeply attached to their children, especially since they had separated from their partners. Their children were their lifeline. The mention of safeguarding issues made them highly anxious about their children being taken away from them. The GPs' intervention to ensure the safety and wellbeing of the children was warranted and correct.

However, the handling of the situation resulted in distress for the patients. One of the participants described the trauma she was subjected to by a GP's behaviour:

Participant: Anyway, I went to see this male doctor. At that time I was in such a desperate situation that I wanted to say to someone that I needed help. So I didn't care whether the doctor was male or female, Muslim or Asian, white or otherwise. I told him about my situation. It was quite a delicate situation. I had certain beliefs about the situation I was going through, and I disclosed these to the doctor. I didn't expect the doctor to agree with me but I wanted to air my views, and what had happened to me, and the reasons why I had gone to see the doctor. I have 3 children. When he heard this that very instant, the doctor laid down his pen. Sometimes, a person's body language scares you. I felt terrified by the way he looked at me. I feared that something was going to happen to me. He said that he would have to discuss my case with a senior doctor and consider whether there were any child protection issues. I was so afraid that I broke down. I said to him that the situation for which I had come to him was already so delicate. On top of that, he was telling me that he needed to speak to a senior about whether there were any child protection issues. I said that I regretted making an appointment with him and that I wanted to leave. He said that I couldn't leave, and that he had to go and speak to someone. He must have gone out of the room for only 30 seconds or a minute but the hell I went through in those 30 seconds – because I was terrified that my children would be taken from me and given to my ex-husband. It was already quite a fragile situation that I went to speak to him about. Rather than giving me any help regarding that, he turned around to me and said, 'On the basis of what you have told me, I need to discuss whether your kids need protection.' I said that I am a competent and confident lady. I know my kids. I would never put them in that situation. I think first of my children. Mothers like us think first of the safety of our children, then we think of our own safety. Having checked with his senior, the doctor agreed that I had taken the right steps and that my children were not in danger. But after that I said that I didn't want his help any more. I didn't want his help because his response was so negative that I thought, 'No, Forget it. I don't want to say anything to you...

Interviewer: Those 30 seconds when left the room must have seemed like an eternity to you?

Participant: it was, it was an absolute eternity. I was like, praying whatever I could, whatever I could chant. I was saying 'God, please, my kids, my kids'...If the GP had made some unfortunate decision, all my hard work for my children would have been in vain. For them, it was a matter of a split second. For me, it was my whole life. They don't realise that.

The patient attributed the lack of understanding shown by this GP to the fact that he was a generalist, whereas the complexities of her personal circumstances demanded specialist care. She felt that he was out of his depth. Her interpretation was that the GP was alarmed by the potential for abuse of the children and felt an urgent need to do something but didn't know what to do. While the GP's concern for the children was justified, in the process he overlooked the needs of the patient for whom he had responsibility and a duty of care. In the end, due to his unsympathetic attitude, she regretted going to the GP.

Concerns about their children being taken away affected the trust these patients had in healthcare professionals and made them less likely to seek treatment from GPs. Another participant expressed a similar experience as above of a GP threatening to separate her from her children and cited this as a major reason for her not visiting a GP or not disclosing her health problems fully:

I agree with what the previous lady said about GPs directing the conversation towards children. I would be in the middle of telling them about my problems, and they will suddenly say, 'We will phone social services.' Then, I would have to hastily retract and say that I am perfectly fine because I am frightened of social services being brought into the picture. I am so scared of my GP now. I am separated from my husband and have three children. I feel afraid about my children being taken away and hesitate before I tell anyone about my problems. To whom do I disclose my problems? Who can we open up to [*if we can't trust the doctors*]? (Breaks down)

The patient had developed an antipathy to being honest and transparent with her GP about her health needs due to the way they had treated her: **'I would rather choke to death than share my problems with them. Our religion, Islam, teaches us that we shouldn't hide anything from doctors. But after coming here, we feel so scared of the doctors that we don't feel like sharing anything with them.'** Her predicament is likely to be shared by other patients. This is a group of highly vulnerable patients who are being alienated by the manner in which they are being treated by some healthcare professionals.

It wasn't only GPs who were criticized for showing a lack of empathy and not offering patients enough emotional support. Doctors and nurses at hospitals, too, were reported to have shown inadequate consideration for patients. The coordinator of the support group for victims of domestic violence described her recent unsatisfactory experience at a hospital. Her sister had been admitted after being extremely unwell. The Consultant in charge of her treatment made an initial diagnosis of tuberculosis. Suddenly, in the evening, the doctor appeared, informed

the patient's family that he now ascribed her illness to Lymphoma, and left immediately.

The abrupt change in diagnosis from tuberculosis to cancer came as a shock to the patient and her family. The doctor's hasty departure and unwillingness to offer more information or any emotional counselling caused acute pain to the coordinator and her sister. They had to deal with this surprising and painful new information all by themselves through that night. The coordinator felt that the manner in which the doctor had communicated such potentially traumatic information to the patient and her family had been insensitive and uncaring. She was angered by the absence of any kind of emotional support from the doctor. Her sister died shortly afterwards. This hurtful episode crystallized into a resolution to lodge a formal complaint against the consultant. However, the result of her complaint was not particularly satisfactory. Such experiences are likely to breed disillusionment and cynicism about the futility of complaining against a system that will not listen. In the extract below, the coordinator explains the thought process behind her decision to complain about her sister's care:

The other issue was about how the doctor, a consultant in the hospital, relayed the news to us, 'Oh, she has not got TB, she has got cancer,' and disappeared, which is unacceptable. On any level, it is unacceptable to do that to somebody. We addressed it immediately with the doctor. As soon as we could, me and my sister, we are the mouthy ones in the family, decided, 'We are not going to leave that'. So we met the doctor. We said to him, 'Do you realise what you did, and that it is unacceptable?' and there was still no apology. The doctor busied himself in trying to justify his actions. We asked him, 'Do you understand what you did there, and the impact it then had overnight, how stressful it was that you just disappeared?' Still, there was no real acknowledgement such as 'Well, I am really sorry. I shouldn't have done that.' Sometimes that is all you want, a human response. He could have said, 'In hindsight, that was not the right thing to do,' and apologised. And then it would have been done with. But he doesn't really care, look at what he is causing. So that was another thing, and it is about educating doctors, and feeding this back into the system.

At the same time, the coordinator took pains to emphasize that such seemingly callous behaviour was not universal. She stressed that the degree of emotional support provided varied, and was dependent on the individual one was dealing with. While highlighting the failings of the first doctor's approach, she also acknowledged that her sister received excellent treatment in the Intensive Care

Unit (ICU). The medical staff in the ICU went out of their way to accommodate the cultural requirements of her family. Her sister's husband did not speak English fluently. There happened to be an Urdu-speaking doctor in the hospital. The medical team in the ICU included this doctor when they attended to her sister. The Urdu-speaking doctor was able to translate and explain things clearly to her sister's husband and the rest of the family. This extra support by ICU staff made a huge difference to her sister's husband and her family. ICU staff also showed consideration for the religious needs of her family. They understood that praying was very important to her family, so they made provision for prayer rooms. The coordinator praised the compassion and emotional support offered by the ICU staff warmly.

The issue of lack of emotional support also surfaced in relation to patients diagnosed with HIV. The inappropriate disclosure of sensitive information to children was compounded by the absence of psychological counselling for them or their parents. The children's lack of knowledge about HIV caused them to be troubled by fearful thoughts and concerns about their own future. While going to school, one patient's son phoned her to ask, 'Mum, my legs are weak. What is the point of being in education? What if you die? Is it genetic? Will I ever have children?' The parents were concerned that their children might attribute any illness, even a minor headache, to the HIV that they feared they had contracted from their parent. The parents felt abandoned by NHS staff. The absence of any psychological support or counselling for them and their children felt like an additional burden.

Theme 4 – Dignity and Respect

Many of the BME participants involved in the focus groups felt that they had not been treated with respect and dignity. The lack of respect and dignity shown to these patients was manifested in different ways. This section reports some of these instances.

4.1 Negligence

Hospital X was highlighted as a particularly problematic provider of care by research participants diagnosed with HIV. One patient explained that when there was an emergency and paramedics tried to take her to Hospital X because it is the nearest hospital, she asked them to take her to Hospital Y instead. She prefers the latter hospital because the staff there treat her with more friendliness and respect. Another participant suggested that these instances of poor care at Hospital X be investigated because there appeared to be a racial dimension to these instances.

One participant narrated a shocking case of negligence by the staff at Hospital X:

'I was admitted to Hospital X. On a Sunday morning, I wasn't washed. I am incontinent, both ways. At the moment, I don't use a catheter because of infections, I use pads. So, on this morning, I wasn't washed. I was just hoisted, because I didn't have my wheelchair, and put on a chair, given breakfast. I kept buzzing, 'Please, can I have a wash?' You can imagine, I was last changed around 7 pm the previous night. The nurses said, 'Oh, we are coming...Oh, no, [name of patient], it is lunchtime, we will wash you after lunch.' It was around 1 pm. Later, I asked them again, 'Now that you have had lunch', and they said, 'Oh, no, no, no, we are busy with a few things. Somebody will be with you. It was 6 o'clock when I was changed. It was really bad for me. Imagine, that was nearly 24 hours in the same pad that was soaking wet. Nobody wanted to come to my room. Because I didn't have my wheelchair, I was not mobile. I was on a chair. I couldn't go anywhere or open the door. I would press the buzzer. If somebody came, I would ask, 'Can I have a wash or just a change, and can you leave the door open?' They would just come and switch off the buzzer, and then they would be gone.'

4.2 Coercion

Coercion by NHS staff was another manifestation of a lack of respect and dignity towards BME patients.

Several patients reported being pestered by NHS staff, to the point of harassment, about when they were going to get their children tested for HIV. Despite the reluctance of the patients, NHS staff reportedly put pressure on parents to agree to have their children tested.

A research participant narrated the experience of a friend of hers, an African woman, who stopped going to her local hospital (Hospital Y) because of the pressure put on her by hospital staff to have her teenage children tested. The participant herself had been asked by NHS staff to encourage her friend to get her children tested. However, her friend refused steadfastly to have her HIV diagnosis revealed to her children. She did not want them to go through the anxieties of having a parent with HIV. Finally, to escape the unrelenting pressure from hospital staff, she chose to leave her job and move to London.

The insistence by NHS staff that parents have their children tested suggests a lack of understanding of cultural differences between White British and African communities.

African patients living with HIV were reluctant to disclose their condition to their children because of pervasive social beliefs about HIV:

'In white culture, they don't understand why you shouldn't disclose to everybody that you are like that but in our culture, you just can't. Because if you tell your children that you are HIV positive, all they see is death.'

Another type of coercion occurred with patients undergoing treatment at NHS hospitals. A participant voiced her displeasure at what she perceived to be undue coercion by NHS staff. She had gone to the emergency department of Hospital X with a chest infection. She stayed at the hospital for one night. She claimed that during her stay she was pressured into taking a HIV test against her wishes. She found out about her diagnosis when she overheard staff outside her room talking about it:

'I went to the emergency department because I was not feeling well. I had a chest infection. They said, 'We have to find out what is wrong with you.' They said, 'We can't find out exactly what is wrong, so we have to do the test for HIV. I said, 'I can't do the test. My husband has to be here because you cannot just wake me up and tell me that I need to be tested for HIV. I asked for my husband to be present because I didn't know my HIV status and I wanted someone beside me to offer emotional support when the news was broken to me. The protocol says that someone is not supposed to force you. I refused, and I told them, 'I am waiting for my husband'. They said, 'You are delaying. We can't do anything. We can't treat you.' I said, 'I am not refusing but my husband has to be here.' At the end, they were, like, forcing me. They said, 'There are patients by your side who are in a critical condition.' Then I said, 'Ok, it is fine. You can do it.' They did it. They were supposed to come and tell me the diagnosis, and they didn't. I found out when I overheard a nurse telling others outside my room. I had been asked not to use the toilets. When I asked to use the bathroom, a nurse came and put a commode in my bed. She was saying outside, "I am scared to touch [name of patient]. She is HIV positive," and that is how I found out.'

When the patient complained, she was accused by NHS staff of being aggressive. She said that an attempt was made to move her to a different room and to change her medication.

The patient (mentioned above) being asked not to use the hospital's toilet facilities because she had HIV, and the nurse's articulation of her fear of touching the patient, point to a need for training for NHS staff about HIV and how it is transmitted. Research participants were in agreement that ignorance about HIV transmission among NHS

staff, expressed in their reluctance to touch patients, materially affected the quality of care offered to patients, especially, BME patients. One patient commented on the deliberate wearing of gloves by NHS staff when handling patients diagnosed with HIV:

'The nurses and the carers would be talking within our hearing, "Be careful when you go in there. Wear gloves." I even ended up telling them, "Being HIV positive does not mean that when you come to me you have to wear gloves. I am not bleeding. Actually, it is better if you wear gloves because that also protects me from you. You come from other patients and touch me. You don't wash your hands." They [NHS staff] can be very, very careless with hygiene. I once ended up with MRSA when I was in hospital for ten months. Now, they are making it big. "That woman, she has got AIDS, and she has got MRSA. Be very, very careful." It is terrible.'

4.3 Discriminatory Treatment by Dentists, General Practitioners, and Receptionists

An African participant stated that her HIV diagnosis was the reason for her being attended to after all other patients by her dentist. She said that she would be given the last possible appointment by her dentist. Even when she had an earlier appointment, say, at 11 am, she would be made to wait until the last patient for the day had been seen. One day, she had an appointment for 10 am and was actually seen at 3.30 pm. When she asked for an explanation, she was told that the dentist was running late. She was not satisfied with this explanation and believed that the delay was because the dental staff had seen the paper on which she had written that she was diagnosed with HIV.

In another example, a female Asian patient expressed her unhappiness at being misrepresented by a doctor. The patient had been advised by a consultant at Hospital X that one of the options being considered to deal with the pain in her neck and eyes was to give her steroid injections. The patient was afraid of taking these steroid injections because she had heard accounts from others that the results were not good, and that the pain had returned. The consultant then wrote on their own to the patient's GP that she did not want to receive any steroid injections. The patient was unhappy at this misrepresentation because that is not what she had said. She had merely said that she was scared of taking the injections, not that she wouldn't take them if the doctor prescribed them.

Another female Asian patient had experienced issues with GPs. She said that they were always in a hurry to get the patient out: **'As soon as you go in to see your GP, they**

just want to get rid of you before you have even sat down. It is like, ‘Hurry up. What’s your problem?’ They don’t want to listen... Looking at how they try to rush through an appointment, and not listen, it is off-putting.’ She felt that there was a racist dimension to the conduct of the receptionists and GPs towards her: ‘There is a bit of racism. When you see the way they speak to white patients, and the way they speak to non-whites, there is a difference. There is definitely a difference. I feel it. And I can communicate with them, but I do sometimes find it really offensive and patronising.’

Since receptionists are the first point of contact for patients, their behaviour has a big impact on patients’ experiences of care. The good work of a doctor or nurse can be undone to a large extent by a rude and unhelpful receptionist. Given the multiple social disadvantages faced by patients from minority ethnic communities, they are likely to be affected more by the unsympathetic and unhelpful attitudes of receptionists.

There was strong agreement among the research participants that one of the areas in most urgent need of reform was the behaviour of receptionists. The rudeness of receptionists in GP surgeries and dental practices has become notorious. Many participants shared stories of being mistreated by receptionists.

One of the participants was appalled with the behaviour of some receptionists at her GP surgery. On several occasions, when she had phoned in to request an appointment, the receptionist had asked her to attend on a particular day. When she had arrived on the day, she had found out that the receptionist hadn’t even booked the appointment in their calendar. It was clear from the receptionist’s actions that they hadn’t listened to her. Sometimes the receptionists had behaved rudely, making her feel that she shouldn’t be at the surgery, and that she was wasting their time.

One participant described the discourteous and domineering behaviour of one of the receptionists at GP A: ‘There used to be a white receptionist who used to ask so rudely (in a very loud voice), ‘WHAT’S YOUR PROBLEM?’ A patient would get scared and retreat, thinking that if I tell her my problem, I am unlikely to get an appointment.’

One of the participants, an Albanian woman, said that there were occasions when she felt that the receptionists at GP B were making fun of her. She felt insulted by their mocking behaviour: **‘Some British people speak rudely about immigrants and don’t have respect for them. I had a good life in my country. I had a job. I have come here to change my life, not to be put down again.’**

Theme 5 – Awareness of the Complaints Process

Awareness of the complaints process among BME research participants was low. Further, there was a general unwillingness to complain except in extreme circumstances.

Some participants felt disinclined to make complaints due to concerns that their future treatment might be affected. Fear of a backlash from the medical profession was a significant deterrent to lodging complaints. Many of the participants in this research project were very frail and vulnerable individuals such as female South Asian survivors of domestic violence and elderly Chinese men and women.

Their relatively greater need for care, and their fear that their care might be jeopardised by criticizing the medical professionals on whom they were so heavily dependent, dissuaded them from speaking out. The prospect of alienating their GP or other healthcare professional filled them with apprehension.

There is a clear need for educating patients that making a complaint will not compromised their care. It needs to be highlighted that expressing dissatisfaction with poor care does not mean that one will get into trouble with healthcare professionals or be denied care.

Cultural factors also played a role in participants' unwillingness to complain. Participants from the Chinese community explained that one of the reasons for their reluctance to speak out against poor care was a cultural deference to people in positions of authority such as doctors. As one participant said, 'In Chinese culture, the doctor is accorded a very high official status. Patients are expected to listen to and to obey the doctor. We rarely make a complaint against a high official.'

Language barriers and lack of confidence in communicating grievances were another reason why BME patients did not complain.

Lack of clear knowledge about the complaints process inhibited some BME patients from registering their unhappiness with poor care. Many said that they did not know how to make a complaint. The crucial part that community-based organisations can play in bridging this gap in knowledge became clear. One Black Caribbean man suggested that organisations like BHA can play an important role in supporting patients in lodging complaints. He said that patients would feel more comfortable in bringing their complaints to the staff of organisations that they are familiar with and that they trust, such as BHA, rather than trying to deal with them on their own. Others said that if they received assistance from their local support group or from organisations like BHA or the George House Trust, they would find it much easier to make a complaint. If someone

informed them about the process, and facilitated the complaint, they would be much more likely to speak out against poor care.

One Asian participant described the thought process behind her decision not to make a complaint and why the support of an organization can matter:

'When you are going through it [the unsatisfactory episode of care], there is too much other emotions and you are thinking, 'I am going to complain about this once I have gone through it,' and then you get through it, and life takes over. You feel emotionally drained. Sometimes, you need the energy, don't you, and that is why it would be useful to have someone say to you, 'Come on, we have got to do this now. You really need to do it.' It drains you quite a bit. It is emotional energy that it takes, it is not only physical energy, but having to regurgitate and rethink about what happened, and go through that whole process, I can understand why people kind of leave it in the end. It is something you feel strongly about but stuff gets in the way.'

BHA's view on this is that support with complaints is not a part of the organisation's remit. Other organisations exist that can support patients in lodging complaints, and which have specialist expertise in this area, such as the local Healthwatch and the Independent Complaints Advocacy. It would not be appropriate for BHA to duplicate their work.

A contributory factor to patients' hesitation to make known their dissatisfaction with poor care was the perception that the complaints process was extremely long and seemingly interminable. One participant said:

'Sometimes I have tried to complain but the process is so long that, in the end, you just give up, and you think it is not worth it. For the children, I will stick to it but for myself, no, because you just get passed on and on and on.'

A related factor was the belief that the complaints process involved filling out a lot of forms, a task for which these patients, already struggling with long term health conditions, did not have the time, energy or courage.

One of the positive reasons stated by participants to explain their decision not to complain was that complaining had been unnecessary since their experience of receiving care had been highly satisfactory. One participant, an elderly Pakistani man, offered his appreciation of the excellent care that he had received from the NHS:

‘Imagine a man who needs two slices of bread. If he gets five slices of bread, he would have to be mad to go and complain. These people go out of their way to care for us. Why then should we go around picking up quarrels?’

Participants who held such views had a high opinion of NHS services and voiced their gratitude for the care that they had received. A middle-aged Pakistani man explained why people from Pakistan might be less likely to complain about NHS services than White British patients:

‘We are from Pakistan. Subconsciously, we compare the healthcare we receive here to the care we received in Pakistan...You have to consider the background we have come from. We didn’t have such facilities there. We are conscious that we have received many facilities after coming here. So, we feel very privileged. Because we didn’t have such facilities before, we are thankful. The British, though, think differently because they know that they have paid money for the NHS. There is a big difference in the way we and British patients think about the NHS. They think, “We have paid the money.” We think, “We are getting treated now. We didn’t get any treatment in India or Pakistan. We are very lucky. We are getting free treatment.” We who have come afterwards think that we ought to be grateful because we didn’t get any treatment at all in India or Pakistan.’

Theme 6 – Lack of proper Investigations and Diagnosis

Some of the strongest criticism by the research participants was directed at the lack of proper investigation and diagnosis of their illnesses by medical professionals.

A female South Asian patient cited an instance of inaccurate diagnosis by a dentist. She had been having pain in her lower jaw for years. She was referred to a dentist at an NHS dental hospital. After numerous tests, the dentist informed her that the pain emanated from one of the wisdom teeth in her lower jaw. The dentist recommended surgery to remove the tooth completely. A date was arranged for this operation. On the appointed day, with the patient on the operating table, the dentist suddenly changed tack and told her that it was too risky to remove the tooth from her lower jaw. The dentist told the patient that the pain stemmed from a tooth in her upper jaw and proposed to remove it. The patient was shocked at this last-minute change of plans but couldn’t argue against the dentist in that situation, so the dentist went ahead and removed a tooth from the upper jaw. The patient voiced her frustration and helplessness thus: ‘I had gone to the hospital for the removal of one tooth, and a different one was removed. At the last moment, they changed the tooth which was to be removed. What could I say?’

The patient was aghast that after three years of treating her, the dentists still hadn't been able to locate the source of her pain accurately.

She doubted the soundness of the dentist's decision to remove a tooth from her upper jaw as she had not experienced any pain in her upper jaw. The patient still has the pain and continues to go to the dental hospital. Her frustration was increased by the dentist's recently changing the diagnosis yet again. This time the dentist said that the pain in her teeth was related to her depression. Despite the severe pain that she experiences, resulting in her tongue swelling up, the dentist has persisted with the depression hypothesis. Her problem remains unresolved.

The dental surgery was not an emergency. The patient was not given sufficient time to make an informed, considered decision. She was not given sufficient opportunity to disagree with the proposed course of treatment. Therefore, the last-minute change of plans was unethical as well as being based in an inaccurate diagnosis of the cause of the pain.

The treatment of Asian women's symptoms by GPs, dentists and doctors in NHS hospitals is a matter of concern. The patient mentioned above gave another example of this. A friend of hers, an Asian woman, was suffering from back pain. She went repeatedly to her GP and was told that it was due to her age (she had crossed 50) and her being menopausal. Eventually, she got fed up and accepted the doctor's diagnosis. When the pain didn't subside, further tests had to be carried out. Finally, the doctors diagnosed that her back pain was actually due to a problem with her discs.

Another female Asian patient who was suffering from depression vented her frustration with GPs attributing any and every ailment to her mental health problems. Whenever she presented with any physical symptom, say, body ache or some physical pain, the GP would say that it was due to her depression and give her anti-depressants. The patient was unhappy because she felt that the doctor was neglecting the possibility that she might have health problems that were unrelated to her depression. The diagnosis of depression, she worried, might mask other existing illnesses. She was also concerned that her physical ailments were being trivialised and were not being treated with sufficient seriousness by the doctor. In the absence of correct diagnosis and treatment, she feared that she might have health issues which might remain undetected and untreated until they were at an advanced stage. For a doctor to discover a disease only after it had reached its terminal stage, she believed, was not fair to patients.

The examples cited above point to a problem of misdiagnosis by some GPs and dentists, particularly in relation to Asian women with mental health problems. This has significant consequences for the health of the patients. Not only are they not offered the right care, incorrect diagnosis can cause underlying problems to fester and worsen their

physical and mental health. A doctors' lack of consideration of a patients' perceived symptoms makes the latter doubt themselves and erodes their already fragile self-esteem. Inaccurate diagnosis, thus, not only delays the administration of appropriate treatment, it also undermines patients' self-belief. One patient summed up her thoughts thus: **'It is not fair that the NHS keeps misdiagnosing the causes of symptoms. This has a negative impact on us. We are forced to believe that we are wrong, that we don't really have the pain, and then, at the end of the day, some other cause of the symptoms is discovered. Doctors should take our concerns seriously.'**

Some patients, diagnosed with HIV, were dissatisfied with the lack of interest from GPs in the investigation and diagnosis of their illnesses. Their illnesses may or may not have been attributable to their HIV infection but when the patient presented with an illness, the GP was likely to ascribe it to their condition. The risk in this approach was that the GP might not investigate for other independent causes of the illness. Unrelated illnesses existing in parallel with the HIV might go undetected. As a patient said, **'It is like HIV is a stamp on all the diseases you have. It is a permanent thing [label] on us.'** HIV might obscure other underlying illnesses.

Some elderly participants in the group discussions admitted that they struggled to remember things. They were more likely to forget appointments. These patients would have liked GPs to take their memory problems seriously and not dismiss them as one GP did with a patient, saying, 'Oh, I forget things as well.' The patient felt that she had been given the brush-off. She was clear that she would have liked the doctor to investigate what was wrong, why she forgot things, instead of assuming that her memory problems were inevitable consequences of ageing.

Theme 7 – NHS consultations, Free Health Checks and 7-day GP Service

Hospital X was commended for its inclusive public consultations. A participant said that the hospital organises these consultations once every two or three months. Different kinds of patients, including patients with different disabilities, are invited. Sign language interpretation is offered for people with a hearing impairment.

There was agreement among the participants that the main reason for low attendance at consultation events was lack of awareness. A need to publicise these engagement exercises more effectively was identified. Participants suggested that organisations like BHA should organise quarterly meetings where service users can be updated with the latest initiatives by the NHS. At these information dissemination sessions, information about relatively new services like the 7-day GP service, about existing but underused services like free NHS health checks, and upcoming consultation events could be shared and discussed.

In keeping with low levels of awareness, participation in consultation events was rare. Very few participants had attended such events. However, one participant who had attended one of these events found it quite beneficial:

‘Yeah, it was amazing. You feel you are being heard. I would like to do that. If we all had a chance to make a difference that would be amazing.’

One participant articulated her concerns about attending consultation events. She felt that she would get singled out because of her Asian appearance and would feel uncomfortable going to such events:

‘Yeah, maybe because of the way I have been treated in hospitals where I get looked at by professional people. If I knew that where I am gonna go there were a few women in Salwar Kameez and scarves, I would probably feel more comfortable.’ She also said that the word ‘Consultation’ makes it sound very ‘snobbish’

This suggests a need for organisers of NHS consultations to show that these events are welcoming of patients from minority ethnic communities, for example, by making provision for interpreters and ensuring that information about the events is disseminated widely. Ideally NHS commissioners, clinicians and managers should go out into communities and meet patients in settings where they feel more comfortable and are able to articulate their concerns and preferences more freely.

Other barriers to attending consultation events included lack of childcare support, especially during the holidays. This was a particularly acute problem for the single mothers who attended this discussion. The participants welcomed the alternative (to their physical presence at meetings) of texting or emailing their comments: **‘Texting is a good way. If I received a text three days before a consultation informing me that there is going to be a discussion on these issues, and that I could add my thoughts by text, that would work for me because I could do it from home.’**

On the whole, the participants were quite positive about the value of consultation events and patient feedback and showed a willingness to engage **‘I receive a text message from my GP after consultations asking me about my experience of visiting the GP surgery that day. I always respond to this request for feedback, that No. 1 is good and no. 5 is really bad. This text always comes**

to me after appointment, and I like it very much. I also like answering the questions because it shows me that the doctors are caring and listen to you.'

The concept of attending consultation events seemed quite alien to the participants. Some of them had experience of researchers and other intermediaries coming to them to elicit their views. However, they had not directly interacted with healthcare professionals, that is, clinicians and managers. Most of them weren't aware of the Patient Participation Groups (PPGs) run by their GPs, or of how to join them. Some spoke jokingly about receptionists not allowing them to attend the PPGs because they might be critical of the receptionists and doctors. One of the participants, an Albanian woman, interpreted the suggestion of patients being constructively and helpfully critical of healthcare professionals as 'shouting' and said that 'it was not good to shout'. Another participant, an African immigrant, responded to this by saying, 'And that is why you suffer. What I have learnt in the UK is that if you keep quiet, you die with it. If you speak out, it will work. This is the nature of England. Back home, if you speak up, they kill you. Here, it is different.' This interesting comment brought into sharp relief the differences among patients in their willingness to engage actively with healthcare services. In their home countries, these patients may not have had the opportunity or encouragement to have a dialogue with the healthcare establishment. Therefore, the idea of interacting with healthcare professionals with a view to improving services may be a particularly novel and alien concept to patients who are new arrivals to the country.

There may be a need to support and encourage them to take on a more active role and to educate them about their responsibilities in co-creating a more responsive health service that meets the needs of patients effectively.

NHS Health Checks

The question about free NHS health checks was greeted with a silence, with participants being unaware of where these checks were held and whether an appointment was required to have these checks.

7-Day GP Service

Most Chinese participants had not heard of the 7-day GP service. There was a low level of awareness of the 7-day GP service among the Pakistani men. The free NHS health checks were not applicable to this cohort as they were all suffering from diabetes.

Participants commented on the need for better communication by practices around their opening times. One participant described her experience of going to a GP on Saturday morning because her son was unwell. She searched online for the GP's opening times and found out that they were open on a Saturday. Upon arriving at the

practice, she was told by the receptionist that Saturdays were only for working people who couldn't visit a GP during the week. She was advised to call NHS 111. This incident highlights the need for the practice to inform their patients about any non-standard services such as the 7-day service. This patient could have been spared the indignity of being refused an appointment and the cost and inconvenience of a wasted journey, and she would have been able to take her son elsewhere where he could have received treatment sooner.

Theme 8 – Lack of Awareness of Rights, Entitlements and Responsibilities

Concerns were raised about a dental practice, specifically, in relation to a dispute between the dentist and a patient about the latter's entitlement to free dental care. The patient, a female Asian lady, had regularly visited the dental practice for some years and had received free dental care as she was on a low income. She was suddenly asked to start paying for her dental treatment after a new dentist took over the practice. The receptionist started questioning the patient about the benefits that she was on. The patient said that she was on the same benefits as before. The patient understood that she was entitled to free dental treatment and had the documents to prove it. The receptionist and the dentist, however, did not accept her explanation. They cancelled her appointments repeatedly and refused to treat her. They threatened to annul her registration with the practice if she persisted in her refusal to pay for her treatment.

This patient had not received any dental treatment for the past two years and she had begun having problems with her teeth. The lady had considered changing dentists but had struggled to find another that was accepting NHS patients. Moreover, there was only one dentist at the practice, so she had no choice.

This incident highlights the barriers that recent arrivals face in accessing appropriate care. Low levels of literacy and poor command of English combined with a lack of awareness of their rights and entitlements to care can make them vulnerable to denial of care. Further, faced with an inability to access care, they might not know who to turn to for advice and support. They might struggle to identify who can adjudicate in case of a dispute with a care provider. Their limited command of English might hinder their efforts to seek and to understand independent, impartial advice. It might also affect their self-confidence and their willingness to assert their rights. Thus, they might remain stuck in an unsatisfactory situation of not receiving the care that they are potentially entitled to.

The discussions uncovered a need for raising the awareness of Asian and African patients about their entitlements to care and for the management of their expectations. Some patients wished to discuss more than one issue with the GP and were disappointed when told that they could discuss only one issue in a 10-minute

appointment. This was particularly frustrating for women who had experienced domestic violence. Due to their fragile sense of self and lack of self-confidence, even ordinary day-to-day activities such as going to the GP were quite challenging for them. Having summoned the courage and made the time to go to a GP, to not be able to discuss more than one issue proved to be deeply disappointing for them. They didn't feel that they had benefited much from their visit to the GP. Many did not go back.

There may be a need for educating patients and managing their expectations about what can be achieved within the constraints of a 10-minute appointment. If patients wish to have more time with the doctor or discuss more than one issue, they ought to be asked to book two consecutive slots. This is common knowledge to most NHS patients but it ought not to be assumed that all patients, especially new arrivals in the country, are aware of this. It may be useful for GPs to disseminate this information more actively. Some GPs already do this. Others would do well to follow their example and actively promote this information.

One of the commonest themes to emerge from the group discussions was participants' desire for more time with the doctor. They wished doctors weren't constantly looking at their watches and trying to rush patients out. One of the participants was unhappy that the doctor had checked her baby but had not given her enough time after the consultation to dress him up. The doctor had requested that she dress the baby in the waiting area so that the next patient could come in. The patient wasn't pleased because the waiting area was cold and she feared that dressing the baby there might expose him to the cold. She would also have liked some privacy while dressing her child. While the doctor's request was justified and reasonable, perhaps they could have suggested that the patient use a spare room, if available at the practice, to dress the baby, instead of the waiting area. The patient ought also to have appreciated the time pressures that GPs operate under, and been more understanding of such a request.

The discussions uncovered an expectation among some BME patients, particularly migrants that doctors should give them more time. One participant, an African migrant, talked about her frustration with having multiple health issues to discuss and not having enough time with the GP to discuss them all. She desired that GPs should be 'educated' that migrants perceive the service to be poor if they are not given enough time to discuss all their problems. This perception may be due to the person's previous experiences of receiving healthcare in their country of birth. Her experience could be misinterpreted as the doctor giving insufficient time because of their nationality or ethnicity and a feeling of being discriminated against.

This view suggests a need for educating patients, especially those new to the country, and managing their expectations. They may need to be informed that they can book double appointments when they need more time.

Equally, there is a need for GPs to consider that some migrants may have experienced violence and conflict and undergone a traumatic and extremely stressful journey from their home country to the UK. As a result, these patients may have greater physical and mental health needs. An equitable approach would require giving them additional support.

In order for GPs to offer this additional support, they need to be aware of their patients' histories. This will require honesty and an act of faith on the part of patients to reveal their past to GPs so that their needs can be accurately assessed. The recent attempts by the Home Office to require NHS staff to provide immigration-related data might reduce trust in the NHS and inhibit migrant patients from disclosing their histories, especially if they involved violence. Further, the Prevent counter-radicalisation strategy might also stop patients from revealing experiences of violence in their previous country if they fear that the doctor might get the wrong impression and over-react.

Another unreasonable expectation voiced by a participant, an Albanian lady, centred on waiting times. She said, **'I have issues with walk-in centres. If I am going to a walk-in centre, it is an emergency. But when you are there, you have to spend more and more time. I am sick. I can't stay in a chair. I need to see a doctor. I need help. But you have to stay there. Nobody cares for you. It is not good.'** Her perception of NHS staff being uncaring might be due to her lack of knowledge of the right services to access in different situations.

Some of the participants mentioned that they had been receiving letters from the NHS stating that they were receiving free medicines, and asking them to pay for the medicines. These participants were asylum seekers. Their understanding was that they were exempt from paying for their prescriptions. One of these participants had phoned the NHS department that was sending these letters and explained her circumstances. This, however, had not stopped the flow of letters. The other participants in the discussion group informed her that she was receiving these letters because her records on the NHS database were wrong. In order to have her records corrected, she was advised to ask for a form (an NHS Low Income Scheme HC2 certificate), complete it and send it back to the NHS. Only then, she was told, would the letters asking for payment cease. This discussion underlined the need for patients to be educated about their entitlements and how to access them. Lack of knowledge of entitlements can force very poor patients to make payments which they can ill afford.

Theme 9 – Inappropriate care and need for additional support

In this section, instances of inappropriate care are discussed along with an examination of areas where additional support from healthcare professionals might be required. Patients likely to be in need of additional support are those with mental health problems, those in need of dental care, and the elderly.

9.1 Mental Health Support

One of the most pressing issues to emerge from the research was that of inappropriate care for mental health problems, and the drawbacks of taking an overly medical, as opposed to social, approach to dealing with mental health problems. Many of the participants who suffered from depression voiced their strong dislike of the anti-depressants that they had been prescribed by GPs. They said that these anti-depressants had strong side-effects that affected their ability to function normally. For example, a woman who had migraines was told by her GP that her headaches were due to her depression. She was given anti-depressants which made her very sleepy. When she took her children to the school or the mosque, she fell asleep sometimes for half an hour in the parked car without realizing it. She stopped taking the anti-depressants due to these side-effects. Her GP reprimanded her for not adhering to the prescribed medication. Because of this censure, the patient did not go to the GP for two years. She tried to manage on her own without any medication because she wasn't willing to accept the anti-depressants' interference with her ability to live a normal life.

Another patient who had three children also experienced similar side-effects. She was unable to function. She couldn't work or look after her children. She tried alternative medication with fewer side-effects but to little avail. Ultimately, she tried to self-manage her depression and migraines. This lady eventually found a local support group for survivors of domestic violence which she had been attending regularly for some months. She found this group very useful. She felt that she was managing better with the support of this group than she did with the anti-depressants. In this group, the attendees learnt about fitness, nutrition, and healthy eating. Participants discussed alternatives to taking medication for depression such as walking, exercise, and voluntary work. (Another organization whose services had proved very helpful to the participants was Manchester Women's Aid.)

The patient discovered this group through her own contacts. She was surprised that GPs were not making patients aware of such groups nor were they referring patients to them. As she described it:

'I am actually amazed, and so thankful to God and to these ladies that they have this support group here. My GP surgery is literally across the road. They didn't even know about the existence of this group. I had to go through many avenues to get here. Thanks be to Allah, I got here. I am so grateful that I did.'

Another patient expressed similar views. She said that:

'There is no link, no communication between GPs and support groups like this. If the support group network worked together with General Practices, it would improve life for so many. And it is a small thing, not a big thing. It won't require forms to be filled out. All that would be required is for GPs to write down the name of someone that patients can talk to.'

This case highlights a problem with the standard medical care for patients with mental health problems. The current treatment that is offered is clearly not suitable for some patients. There may be a need for GPs to consider alternative medication with less severe side-effects or non-medical approaches to dealing with mental health problems. One participant commented that the current medical model wasn't holistic, that it didn't look at the person as a whole. Another participant remarked on GPs' over-reliance on medication and the under-utilisation of non-medical options.

When asked whether doctors' lack of awareness of local support groups prevented them from referring patients to these groups, the participants replied that GPs asked patients to find out about these groups on their own. Doctors told patients that information about support groups could be found on the Internet and advised them to search on their own. Patients were advised to self-refer themselves to these organisations. However, this advice was deemed to be inadequate by some of the participants. One lady had frequent migraines. The light from computer screens hurt her eyes and made her headaches worse. So, she avoided computer screens and was unable to search for material on the Internet. The practice of asking patients to look information up on the Internet is based on the assumption that patients have access to a computer and Internet connectivity, and that they are technologically literate enough to find the information online.

Besides special interest groups, another source of support for these patients was the services provided by the local council. One of the participants was generous in her praise for the services offered to which included participating in a Sure Start Group,

joining a parenting group, and training courses in volunteering and working as an interpreter. She found these developmental opportunities highly beneficial and empowering. Commissioners of healthcare perhaps need to look more widely at local authorities and social care providers and consider whether a joined-up approach might better meet the needs of patients and improve outcomes.

Patients with mental health problems sometimes need additional support from GPs. When this support is not forthcoming, it feeds the perception that GPs lack sympathy for patients. To cite an example, a participant with severe mental health problems was given a phone number for a specialist service by the GP and asked to contact them herself. The patient would have preferred that the GP contact the service on her behalf. In her emotionally fragile and vulnerable state, she found the ordinarily straightforward task of calling up a health service and asking for help daunting. As she described it, **'When you are going through such a difficult situation, when stepping outside the house is a difficult task for you, phoning a number is like climbing a tall mountain. You wonder if you can do it or not.'**

An additional challenge for her in calling up the health service was the shame and stigma of admitting that she was a victim of domestic abuse. If the GP had rung the service on her behalf within their 10 minute appointment, explained the issues she was facing, and asked them what services they could offer her, she would have felt comforted and helped. The GP's not going the extra mile and asking her to do something which, in her fragile state of mind, was too difficult for her was viewed as not being particularly helpful. It strengthened her perception that she wasn't getting much support from the GP and that that visiting the GP was pointless. Another participant echoed this lady's feelings: **'I liked the way you described it. That is exactly how I feel. It takes a lot of courage just to make that phone call, just to make that appointment and go to the GP. And when you are treated like that, you think, 'I haven't got the time'. Because after the appointment you just have to get up and manage it yourself, so you may as well do it before that and not go through the hassle.'**

9.2 Provision of Dental Care

Dental services were identified as a major source of concern. Two Asian participants, a mother and a daughter, spoke about being made to wait for 3 hours for a T-bar. The dentist's explanation was that he had given them an injection and they needed to wait for three hours for the injection to take effect. The dentist made them wait until he had seen all the other patients and then saw them before the close of day.

When the mother and daughter subsequently changed dentists, they were seen 15 minutes after being given injections, casting doubt on the previous dentist's explanation.

Further, the first dentist extracted two teeth even though the patient had agreed to the removal of only one. He did this both with the mother and the daughter.

After removing the first tooth, he said that it was the wrong one, and then proceeded to remove another tooth. Since the original agreement had been to remove only one tooth, he made the patient sign a paper retrospectively to prove that the patient had wanted both teeth to be extracted. The participants did not lodge a complaint because they were new to the country and did not know the NHS treatment process and their rights and entitlements as patients.

9.3 GP Appointments – Older People

The research highlighted the need for GPs to consider giving extra time to elderly patients. Elderly patients might need more time to talk through all their issues. They might meander before broaching their main concern. Expecting them to be direct and succinct with their concerns may not work, and may even prove counter-productive if it causes patients to suppress relevant background information in response to perceived pressure to be brief. A more patient approach might be required with them. In a group discussion with elderly Chinese participants, one person commented, 'Sometimes they [elderly Chinese patients] can't just directly say what they have, their problem. To go directly to a very big problem is not easy. It is better to have some gentle talk about it, and then come to the issue.' This suggestion for giving elderly patients more time was echoed by a Black Caribbean participant from another focus Group who said: 'Sometimes communication is a problem. The doctor will ask you how you are feeling. You say, 'Oh, I am not so well. I didn't sleep at night. I woke up 3 times, went to the toilet, my head is... You know, time is going, and you have still not identified where the problem is. By the time the doctor asks what it is. 'Oh, my stomach,' the time is gone. So, sometimes the doctor should give you time. Because we don't know how to explain. You want the doctor to understand you, where you are coming from.'

Some elderly participants in the group discussions admitted that they struggled to remember things. They were more likely to forget appointments. This suggests a need for additional measures to support them such as a reminder text before an appointment.

Theme 10 – Sources of health-related Information

In relation to the sources of health-related information used by the participants, most of them reported using a combination of the Internet, GPs, and family and friends, including support groups. The Internet evoked ambivalence and mixed responses, with some participants identifying it as their first port of call while others were sceptical about the reliability and usefulness of the information available online. Participants who were active users of the Internet for health-related purposes explained that they searched online for information first to ascertain whether consulting a GP was advised for their health condition.

If home remedies were available, and the problem could be solved at home, there was no point in waiting for a two-week appointment with the GP. Also, the Internet might provide all the information that the patient needed. However, if they wished to obtain more information or if they wanted to speak to a person, then they would consider seeing their GP. The accessibility of the Internet was cited as a reason in favour of using it as the first source of information. The NHS Choices website, in particular, was praised by two participants for being a source of accurate health information.

Some participants did express reservations about searching for health-related information online, saying that they were concerned about misinformation and not knowing who had put the information out there. Some also said that the abundance of information on the internet had a downside. Reading about all the potentially worrisome symptoms and causes of diseases confused and scared them.

Family and friends, especially, those who had gone through similar experiences, were identified as another source of information. Issues were also discussed, and information shared, with other members support groups.

There was strong agreement among the participants in relying primarily upon their GPs and other medical professionals for health-related information and advice. One participant, a Pakistani man, said that after coming to the UK, he had left behind the home remedies and self-treatment that were quite popular in his home country. Searching for health-related information on the internet wasn't a common practice among these participants, with one person saying that if the information wasn't from an authority in the area, he wouldn't take it. Taking advice from family members and friends, especially those who had experienced that health condition, a practice common in many Asian countries, seemed to have fallen into disuse. As one participant put it: 'In our countries, if a person falls ill, one acquaintance will come to them and suggest that they try treatment A.'

Another will say that they had a similar illness and suggest a different treatment. In the end, the patient gets fed up and prays to God that he be saved from such friends. Thank God, we are out of that situation now.'

Theme 11 – Language Barriers

In this section, the issues around language barriers and the provision of interpreters are explored.

A research participant, an Albanian woman, spoke about the difficulties that her friend, also an Albanian, had faced in seeing her GP. Her English was poor, and she found it difficult to communicate her requirements to the receptionists. She requested an interpreter but was unable to obtain one. At some point, the receptionist started shouting at her (whether the receptionist was shouting in a futile but well-intentioned effort to make herself understood or whether she had become irate is not clear). The patient then phoned her friend, the research participant, who was attending college at the time.

The participant had to leave college and rush to the GP to help her friend as her son was seriously unwell. Her friend had arrived at the surgery with her son needing urgent treatment for a stomach infection. The practice may have been able to arrange an interpreter if they had had advance notice. In the event, they were unable to find an interpreter on the spot.

It may have been helpful to the patient if the receptionist had considered the use of telephone interpretation services if no interpreter was available at such short notice. It may be useful for receptionists, when no other recourse is available, to consider the use of software such as Google Translate to bridge the gap in urgent situations such as the one described above. The participant did acknowledge that she herself had been able to obtain appointments and had not faced any problems in seeing a doctor. It seems, therefore, that her friend's difficulties resulted chiefly from her lack of facility with English. Two other participants also spoke about not being able to obtain an interpreter despite requesting one. Both said that they were forced to rely on friends and family to interpret for them.

Participants from the Chinese community described language barriers as the most salient issue affecting the quality of healthcare. The participants said that most Chinese speakers they know seek Chinese-speaking GPs and dentists, so communication is ordinarily not a problem. A local GP surgery which has Chinese-speaking doctors attracts a lot of these patients. Language issues present a problem if patients go to a hospital for emergency, unplanned visits unaccompanied by an English-speaking friend or family member.

For planned visits, the hospitals are usually able to provide an interpreter, and the participants generally found the quality of the interpreters acceptable.

These Chinese-speaking participants were unable to use the NHS 111 service because they couldn't speak English. Even requesting an appointment with a GP was a challenge for them due to their inability to speak English. The GP might be Chinese-speaking but the receptionists may not be. These patients turned to the Chinese Health Information Centre (CHIC) for support with interpretation. They contacted the staff at the CHIC and requested them to call the GP on their behalf. The difficulty in understanding communications in English extended to situations where patients were referred to specialists and received letters informing them about their appointments. They were unable to understand these letters. Again, they were forced to fall back on CHIC. In previous focus groups carried out by other researchers, the participants had repeatedly requested that routine medical letters be translated into Chinese before they were sent out. This has not happened yet.

During the survey, it was identified that there are a number of BME patients who can speak some but not fluent English.

These patients did not themselves feel the need for an interpreter but it became clear while speaking to them that they could not articulate their health problems fully or clearly enough, and that they could do with assistance from an interpreter.

One of the participants, a Pakistani man, was displeased by the refusal of Asian staff at his GP surgery to assist Hindi or Urdu speaking patients by conversing in their native tongue. The man said that he knew Asian staff in his GP surgery who could speak Hindi or Urdu and who could have helped patients who didn't speak English, but they didn't. Even though he knew that they could, the staff pretended that they couldn't speak Hindi or Urdu. The participant narrated an incident to illustrate this unhelpful attitude of the British Asian staff:

'There was a patient, an Asian woman, who had come to collect her prescription. She regularly receives 3 medicines from the GP but on that day there were only 2 medicines listed on her prescription. She spoke to me and I suggested that one medication might have been missed out in error. I referred her to the receptionist. When she asked the British Asian receptionist, in her native tongue, about the discrepancy, the receptionist said that she didn't understand her query. The Asian woman got angry and swore at the receptionist in her own language. The receptionist, who, a moment ago, had been unable to understand the patient now suddenly seemed to be able to understand her and confronted the patient for swearing at her. I asked the receptionist, "You said that couldn't understand Punjabi or Urdu. The poor woman doesn't speak English you could so easily have helped her and explained what she had to do in Punjabi or Urdu."

I don't know whether the receptionist considered it shameful or beneath her to speak in Punjabi or Urdu. Some people have these snobbish attitudes that speaking English gives them a higher status and prestige, and that speaking a different language makes them a lesser human being. Why do they feel that they are lowered in status by speaking Punjabi or Urdu?'

The Pakistani participants thought that the inability to speak English fluently could be an impediment to obtaining urgent care. While a lack of English could hinder their efforts to obtain care in routine situations, they could be even more severely disadvantaged in situations where care was required urgently.

As one participant explained:

"If a patient needs an urgent, same-day appointment with a GP, and phones the surgery to request it but is unable to explain their symptoms clearly enough to convince the receptionist or the doctor to give them an urgent appointment, their condition could get much worse. The patient might be in a lot of pain and discomfort, but if they can't communicate the severity of their symptoms well enough to persuade the person who will decide whether or not to give them a same-day appointment, the patient will have to suffer in silence."

Thus, their lack of competence in English, which might be a minor disadvantage in routine situations, might become a major hurdle in situations requiring urgent care. Hence, the ready availability of interpretation facilities is a vital necessity for BME patients.

SECTION 3 – CONCLUSION

BHA has documented the experiences of BME patients that have accessed health services over the last 12 months.

The findings from this research indicate that the majority of BME participants view their overall experience of care to be positive and not influenced by their race or ethnicity. However, single incidents of poor quality care and discriminatory practice were identified which obscure the good experiences of the majority.

A number of issues which were identified in previous patient engagement exercises are identified as issues of concern within this report including:

- Poor treatment of patients diagnosed with HIV and a lack of training of NHS staff on the transmission of HIV.
- A lack of awareness of the complaints process relating to the provision of health care and in some instances a reluctance to complain.
- The need for additional time for a GP appointment.

There has been a significant change in the make-up of the BME population in Manchester which will provide challenges in the provision of health services at a primary and secondary level. BHA sets out a number of recommendations below which will assist in tackling the issues raised in this report.

SECTION 4 - RECOMMENDATIONS

The following recommendations reflect on the findings of the research and attempt to recommend changes to improve the experiences of BME groups when accessing health service. An attempt has also been made to align the recommendation to MHCC's commissioning strategy aims.

4.1 Improve the health and wellbeing of people in Manchester

People living with mental health conditions

- Psychological support should be available for people living with long term conditions such as HIV and cancer. Such counselling should be made available to patients as well as members of the family including children.

Older People

- Some elderly participants in the group discussions admitted that they struggled to remember things. They were more likely to forget

appointments. These patients would have liked GPs to take their memory problems seriously and not dismiss them as an inevitable consequence of ageing. There is limited information on the impact of dementia on BME groups but GPs should be proactive in diagnosing possible cases of dementia within BME groups.

- Hospital trusts should consider trialling the translation of routine correspondence to patients, whose first language is not English. This could assist in meeting the differing communication needs of patients as well as fulfilling obligations within the accessible information standard.

Development of Social Prescribing Programme

- More people with long term conditions are seeking alternatives to medication and this was evident from the responses to the questionnaire. There is a need for GPs to develop social prescribing programmes to support their patients with long term health conditions. The introduction of Community Links in North Manchester is a starting point in establishing a good way of GPs referring their patients to local support groups to improve their health and wellbeing. However this programme needs to ensure it engages with local voluntary and community sector organisations and particularly those that provide services for BME groups

Provision of Interpretation services

- GPs and receptionists should proactively and tactfully suggest or offer the use of interpreters where they feel that the patient is unable to communicate their concerns accurately and fully to the doctor, and where this might make it more difficult for the doctor to make an accurate diagnosis.

Access to Health Information and Services

- There should be a greater promotion of reliable sources of online health information for members of the public as many are now using the internet to access information.
- There should be greater promotion of health checks within BME communities as many are unaware of NHS health checks.

Improvements in the Complaints Process

- Organisations that provide support and advocacy related to health such as Healthwatch and the Independent Complaints Advocacy should promote their complaint support and advocacy role more actively to BME organisations and their service users.
- There is a perception by some BME patients that the complaints process of healthcare providers is an overly lengthy process that requires complicated forms to be completed. This view needs to be countered with accurate information about the simple, straightforward and relatively quick nature of the complaints process at many healthcare providers.
- Data from formal NHS complaints should be stratified by the ethnicity of complainants. It might be useful to analyse the ethnic breakdown of the number of complaints lodged against the healthcare provider, the length of time taken for resolution of formal complaints and patient satisfaction with the outcome of complaints and comparisons be made between BME and White patients.

4.2 Ensure services are safe, equitable and of a high standard with less variation

People living with or affected by HIV

- From current practice it is recognised that stigma and discrimination about HIV can be tackled through community based or community focused initiatives that provide accurate information on HIV transmission and information on access to health care. Little however appears to have been undertaken in work places or health services to tackle stigma or discrimination in an institutional setting. This needs to be rectified, particularly in health services where some individuals living with HIV face inferior services from their GPs, dentists and hospital care. Within healthcare services, codes of practice and professional conduct need to be in place and enforced to ensure there is no breach of the Equality Act or the Human Rights Act. This is particularly relevant to breach of confidentiality and inappropriate disclosure of an individual's HIV diagnosis amongst non-clinical staff in a hospital setting and in relation to family members including children.
- Standardised guidelines on infection control should be available and applied to reduce any stigma-enabling anxieties that health care workers may have

about the transmission of HIV and other illnesses. The consistent use of such guidelines will also help to protect the identities and rights of patients.

- MHCC is recommended to share the findings of this report with Hospital X. This is particularly important as arrangements are in place for Hospital X to assist in improving practice and care at a neighbouring hospital but there are issues that Hospital X needs to look at improving.
- It is recognised that NHS England has responsibility for commissioning dental services and the issues related to poor dental care of patients living with HIV should be raised with them. However in 2015 Healthwatch Leeds, in conjunction with service users from BHA for Equality, produced a report - 'Access to Dental Care for People Living with HIV in Leeds – setting our recommendations for improvement in dentistry practice. The recommendations have clearly not been implemented as the negative experiences of patients in Manchester replicate those included in the Healthwatch report. NHS England is recommended to review the report and implement its recommendations.

Interpretation services

- Interpretation is time-consuming, so receptionists and GPs should consider allotting more time than the standard 10 minutes when attending to patients who need interpreters. While some GPs already do this, some variability was noted. It is desirable that practice in this regard is uniform.
- The availability of sign language interpreters for the deaf in GP surgeries and hospital settings was identified as another area that needs to be addressed as a matter of urgency. A deaf participant described her extreme frustration with the lack of interpreters when she was in hospital and the consequent difficulties that she experienced in communicating with hospital staff. She said that this issue had been raised several times in the past but there had been no change in NHS practice.

4.3 Enable people and communities to be active partners in health and wellbeing

Improving Engagement with Patients and the Public

- There is a lack of awareness of consultation sessions that are organised by MHCC. Alternative ways should be sought to involve members of the public. Participants suggested that VCSE organisations like BHA for Equality could have a role in undertaking this work.

- It was recommended that the use of texting could be another way of gathering views from those people who are unable to attend meetings in person
- MHCC should consider how best to promote future consultation events through GP practices.

4.5 **Achieve a sustainable system**

People living with mental health conditions

- Better training should be offered to GPs to support women seeking psychological assistance who have faced domestic abuse. This should be embedded into training programmes for GPs alongside safeguarding training.

GP Appointment system

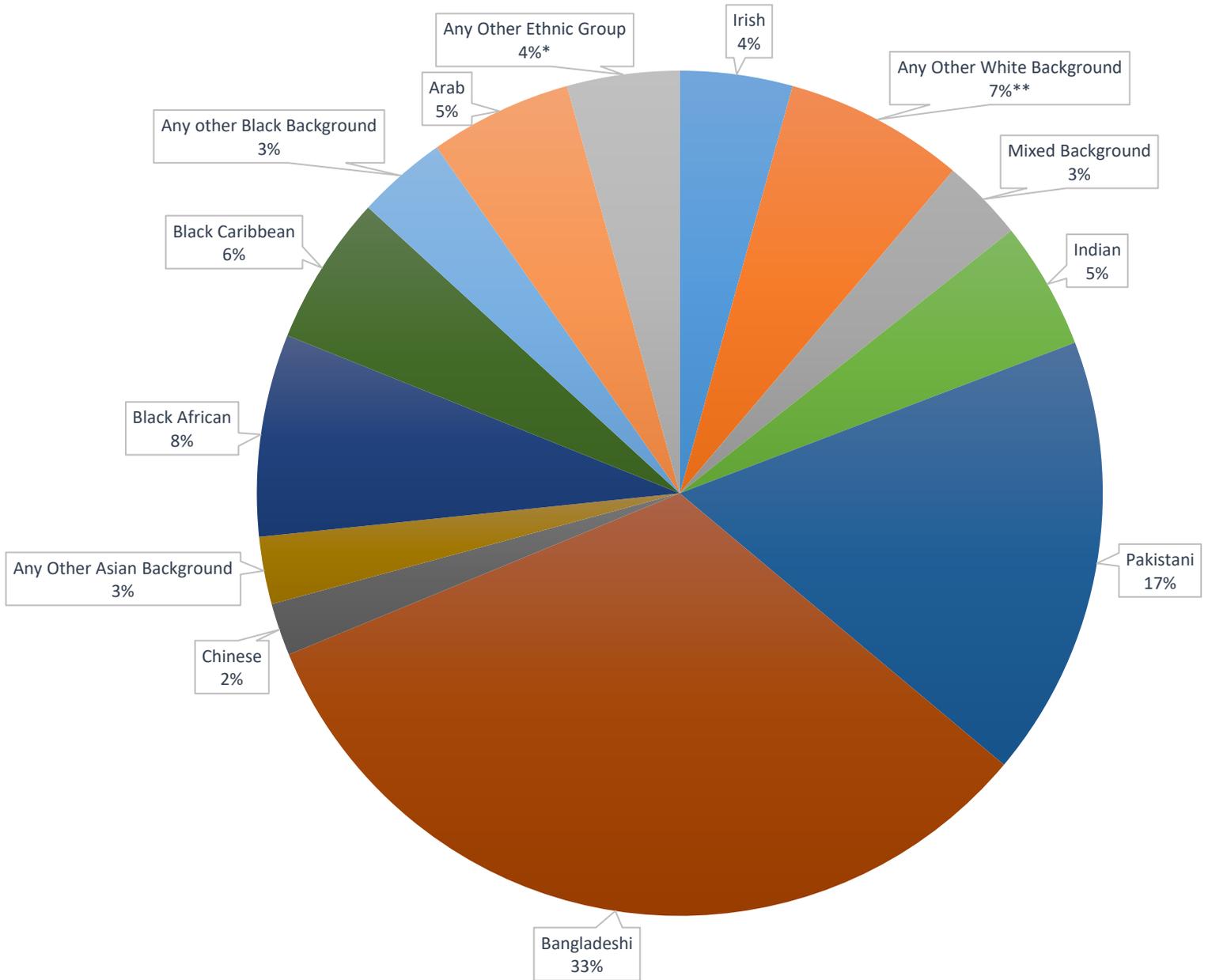
- There is a need to educate patients and manage their expectations about what can be achieved within the constraints of a 10-minute appointment. If patients wish to have more time with the doctor or discuss more than one issue, they ought to be asked to book two consecutive slots. This is common knowledge to most NHS patients but it ought not to be assumed that all patients, especially new arrivals in the country, are aware of this. It may be useful for GPs to disseminate this information more actively but it is recognised that some GPs already do this. The research also highlighted the need for GPs to consider giving extra time to elderly patients.
- The research underlined the need for patients to be educated about their entitlements and how to access them. This is particularly the case for individuals who are new arrivals into the country

Training for Health Staff

- Improved training for hospital doctors in communicating the diagnosis of health conditions in an empathetic way.
- Better customer service by GP receptionists has the potential to make a difference to the experiences of patients. Healthcare providers could learn from exemplars of outstanding customer service from the private sector.

Appendix 1

Ethnic Origin of Participants - Questionnaire survey



*In this category some individuals did not state their ethnic origin but this group included people of Iranian and Persian descent.

** In this group not all participants stated their ethnic origin but this group comprised those identified as European, Polish, Lithuanian, Danish, Portugese and Spanish.

Appendix 2

BME Patient Experience Survey

What is the survey about?

This survey is to find out about **your experiences** of receiving healthcare. We are interested in your experiences as you are a member of a Black or other minority ethnic community in Manchester. Your feedback may be used to help develop and improve NHS services.

Instructions

1. Please complete the survey **only if** you have received healthcare (that is, visited a General Practice, a dental practice, a hospital or a community health clinic) **within the last 12 months**.

Please choose an experience which stands out in your memory and answer all the questions in relation to **this one** experience **only**. The experience you choose to focus on can be either good or bad.

2. **Your answers will be treated in confidence.**

3. For each question please tick clearly inside the box / boxes.

Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box / boxes.

If you select the *Other* option, please explain your choice in the box below the option.

BHA for Equality working in partnership with NHS North, Central and South Manchester Clinical Commissioning Groups

Overall Experience of Care

1. I would describe my experience of receiving care as:

- Very good
- Good
- Neither good nor bad
- Bad
- Very bad
- Don't Know

2. I feel that I was treated with **respect and dignity** by the NHS staff treating me.

- Strongly Disagree
- Disagree
- Neither Agree nor Disagree
- Agree
- Strongly Agree
- Don't Know

Influence of Race / Ethnicity on Experience of Care

3. I believe that the quality of care that I received was influenced by NHS staff's perceptions of my (**tick all that apply**):

- Nationality
- The language I speak
- The colour of my skin
- Religious beliefs (faith)
- The quality of my care was not affected by any of these factors

Go to Q. 5

- Other (please specify)

4. Please explain how the quality of care that you received was influenced by NHS staff's perceptions of your nationality, culture, religious beliefs, etc.

5. NHS staff made incorrect assumptions about my nationality, culture, religious beliefs, etc. which affected my experience of care.

- Strongly Disagree
- Disagree
- Neither Agree nor Disagree
- Agree
- Strongly Agree
- Don't Know

6. I feel that I received emotional support from the NHS staff treating me (that is, NHS staff were caring and showed concern for me and my health condition).

- Strongly Disagree
- Disagree
- Neither Agree nor Disagree
- Agree
- Strongly Agree
- Don't Know

Involvement in Decisions about Care

7. I was involved as much as I wanted to be in the planning of my care.

- Yes, definitely
- Yes, to some extent
- No
- I didn't want to be involved in the planning of my care

Other (please specify)

8. I was given a range of choices for treatment.

- Yes, definitely
- Yes, to some extent
- No
- I didn't want to be given a range of choices
- Other (please specify)

9. I was informed about the costs, risks and benefits of different treatment options.

- Yes, definitely
- Yes, to some extent
- No
- I didn't want to be informed
- Other (please specify)

Raising Concerns or Making Complaints about Poor Care

10. I am aware that I can make a complaint if I am unhappy with the care I receive.

- Yes **Go to Q. 11**
- No **Go to Q. 14**

11. Please state the different ways you know of making a complaint.

12. I feel comfortable about making a complaint.

- Yes
- No

13. If you have made a complaint about the care you received, please give details of your complaint (your answer will be kept confidential).

14. If you wanted to make a complaint about the care you received but did not, please say why (your answer will be kept confidential).

Sources of Health Information

15. When you need information about your health condition, please select the sources from the list below that you ordinarily use to get the information (**tick all that apply**).

- GP
- Dental Practice
- Hospital
- Community Health Clinic
- Pharmacy
- NHS 111
- NHS Choices
- Other sources on the Internet (online articles, reviews, blogs, etc.)
- Newspapers or magazines (print media)
- Religious, cultural or other community group
- Family or friends
- Other (please specify)

Experience of Provision to Meet Patients' Communication Needs

16. During my visits in the last 12 months, I needed the services of an interpreter.

- Yes [Go to Q. 17](#)
- No [Go to Q. 19](#)

17. When I needed an interpreter, I was able to get one.

- Yes
- No

18. Please rate the ease of getting an interpreter.

- Very difficult
- Difficult
- Neither difficult nor easy
- Easy
- Very Easy

- Don't Know

19. My additional communication needs (for example, sign language, large print, easy read version, translations, etc.) were met by the care provider.

- Yes, definitely [Go to Q. 21](#)
- Yes, to some extent [Go to Q. 21](#)
- No [Go to Q. 20](#)
- I didn't have any additional communication needs [Go to Q. 21](#)

20. Please say how your additional communication needs were **not** met by the care provider.

Long-standing Health Conditions

21. I have a long-standing health condition.

- Yes [Go to Q. 22](#)
- No [Go to Q. 24](#)

22. If you have a long-standing health condition, please say which **condition/s** you have (**tick all that apply**).

Alzheimer's disease or dementia	High blood pressure
Angina or long-term heart problem	HIV or Other Sexually Transmitted Diseases
Arthritis or long-term joint problem	Kidney or liver disease

Asthma or long-term chest problem	Learning disability
Blindness or partially sighted	Long-term back problem
Cancer in the last 5 years	Long-term mental health problem (depression, Bipolar disorder, Schizophrenia, etc.)
Deafness or severe hearing impairment	Long-term neurological problem (stroke, Parkinson's disease, Multiple Sclerosis, etc.)
Diabetes	Another long-term condition not listed here (please specify)
Epilepsy	Prefer not to say

23. Please say how health and care staff can help you in managing your long-standing health condition better.

Free NHS Health Checks

24. Free NHS Health Checks are for people aged 40-74 years of age who are not taking medication for a long term health condition such as diabetes, high cholesterol or heart disease.

If you are eligible for a free NHS Health Check, please say whether you have had one in the last 5 years.

- I am not eligible for a free NHS Health Check
Go to Q. 26
- I am eligible and have had a health check in the last 5 years
Go to Q. 26

- I am eligible and have **not** had a health check in the last 5 years
Go to Q. 25

25. If you are eligible for a free NHS Health Check but have **not** had one in the last 5 years, please say why not.

Awareness of the 7-day GP Service

26. I am aware of the 7-day GP service.

- Yes **Go to Q. 27**
- No **Go to Q. 28**

27. I have used the 7-day GP service.

- Yes
- No

Experience of Participation in Consultation Events

28. I have taken part in consultation events to improve healthcare services.

- Yes **Go to Q. 30**
- No **Go to Q. 29**

29. If you have **not** taken part in consultation events to improve healthcare services, please say why.

30. If there is anything else you would like to tell us about your experiences, please do so here.

About You

This information **will not be used to identify you**. We use it to see whether different groups of people are having different experiences of NHS services.

31. Are you male, female, or other?

- Male
- Female
- Transgender
- Other (please specify)

- Prefer not to say

32. What is your **year of birth**?

(Please write in) e.g.

1	9	3	4
---	---	---	---

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33. What is your religion?

- No religion
- Buddhist
- Christian

- Hindu
- Jewish
- Muslim
- Sikh
- Other
- Prefer not to say

34. Which of the following best describes how you think of yourself?

- Heterosexual / Straight
- Gay / Lesbian
- Bisexual
- Other
- Prefer not to say

35. Do you have a disability?

- Yes
- No
- Prefer not to say

36. What is your ethnic group? **(Tick ONE box only)**

a. WHITE

- English / Welsh / Scottish / Northern Irish / British
- Irish
- Gypsy
- ROMA
- Irish Traveller

- Any other White background, **write here**.....

b. MIXED / MULTIPLE ETHNIC

GROUPS

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other Mixed/multiple ethnic background, **write here**.....

c. ASIAN / ASIAN BRITISH

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background, **write here**.....

d. BLACK / AFRICAN / CARIBBEAN /

BLACK BRITISH

- African
- Caribbean
- Any other Black / African / Caribbean background, **write here**.....

e. OTHER ETHNIC GROUP

- Arab
- Any other ethnic group, **write here**.....

37. Please tell us the postcode where you live.....

38. Please tell us where you received your healthcare (the name of the GP / Dental Practice / Hospital / Community Health Clinic, etc.)
.....

Please check that you have answered all the questions that apply to you.

Thank you very much for your help. Your response is received gratefully.

BHA is a charity which exists to improve health and social care equality and support BME, marginalised and disadvantaged individuals, families and communities to improve their health and wellbeing.

