Older BAME people's experiences of health and social care in Greater Manchester

LESSONS FOR PRACTICE AND POLICY

By
Dr Bethan Harries, Scarlet Harris, Natalie-Anne Hall with Natalie Cotterell

With a foreword by Maqsood Ahmad
Older BAME people's experiences of health and social care in Greater Manchester

LESSONS FOR PRACTICE AND POLICY

By
Bethan Harries, Scarlet Harris, Natalie-Anne Hall with Natalie Cotterell

February 2019
Acknowledgements

We would like to express gratitude to the community organisations and participants that helped facilitate the focus groups for their time and generosity: the North Manchester Black Health Forum, Asian Elders Resource Centre and the Indian Association Oldham. Also thanks to the BHA for Equality in Health and Social Care for sharing their report and to members of local public health teams for their interest in this work.

Many thanks to the Manchester Statistical Society for funding this research under their Campion Grant scheme.

About the authors

Dr Bethan Harries is a Lecturer in Sociology at the University of Newcastle and an honorary fellow of the Centre on Dynamics of Ethnicity at the University of Manchester. Her research focuses on racism and inequalities and the social and cultural conditions in which these are produced. She has a particular interest in generational differences in understandings and experiences of racism. She is the author of a number of public policy reports and has published extensively in academic books and journals.

Scarlet Harris is a PhD candidate in Sociology at the University of Glasgow and a visiting associate of the Centre on Dynamics of Ethnicity at the University of Manchester. Her doctoral research considers racism, anti-racist work and responses to Islamophobia in the two cities of Glasgow and Manchester. She has published in leading Sociology journals.

Natalie-Anne Hall is PhD candidate in Sociology at the University of Manchester. Her doctoral research focuses on the role of social media in engagement with new right-wing sentiment, particularly among the middle-aged to older population in the UK. Originally from Australia, she has spent 5 years living in Japan, as well as working for HM Inspectorate of Prisons, the former Australian Department of Immigration and Citizenship, UNESCO Bangkok, and as a professional translator.

Natalie Cotterell is a PhD candidate at the University of Manchester and is associated with the Manchester Institute for Collaborative Research on Ageing (MICRA). Her doctoral research is exploring experiences of social isolation and loneliness among older people from different ethnic backgrounds. Her broad research interests include: healthy ageing, socioeconomic inequalities, and participatory methods.
## Contents

Foreword by Maqsood Ahmad ........................................................................................................ 4  
Executive summary ....................................................................................................................... 5  
1. Introduction................................................................................................................................ 6  
   1.1 Older BAME populations, health & social disadvantage ....................................................... 7  
   1.2 Understanding low uptake of services amongst the BAME population ............................. 8  
2. Aims and approach of this study .................................................................................................. 9  
   2.1 Census and survey data ......................................................................................................... 9  
   2.2 Focus groups ...................................................................................................................... 10  
3. The growing needs of older BAME people in Greater Manchester ........................................ 11  
   3.1 Are needs being met? ........................................................................................................... 16  
4. Experiences of health and social care: an older BAME perspective ...................................... 17  
   4.1 Unequal Treatment .............................................................................................................. 18  
   4.2 Communication and decision making ................................................................................ 20  
   4.3 Bodily Integrity: the right to choice and control ................................................................. 27  
   4.4 Complaints procedures: being or becoming the ‘problem’ ............................................... 29  
5. Discussion and recommendations ............................................................................................ 33  
   Moving forward ....................................................................................................................... 33  
6. References ............................................................................................................................... 36
Foreword

Greater Manchester has a vibrant and diverse community that brings with it a rich culture and language. Devolution brings an opportunity to support and develop group and communities that have often been forgotten or left out of mainstream service provision. Older Black, Asian, and Minority Ethnic (BAME) people are some of those groups that can and should benefit from The Health and Social Care Partnership, which was born out of the devolution concept.

This report is timely when we are embarking on addressing health inequalities in Greater Manchester and is an opportune reminder of the Health and Social Care Act 2012 that for the first time brought in a duty to tackle health inequalities and promote engagement. The report also links to the Equality Act 2010, which makes a powerful case for ensuring that the protected characteristics, including race, faith, gender and sex, need to be considered when designing meaningful and effective services provision.

To help the professional community meet their legal and moral obligations the report’s findings highlight a number of important factors. Decision makers not only need to take notice of these findings, but also need to allocate appropriate resources to ensure that the conclusion and recommendations of the findings are effectively implemented. In fact, the findings of this report highlight an excellent opportunity to co-design services within Greater Manchester.

I strongly recommend to my senior colleagues not only to embrace the findings of this report but to use them to their advantage by directly working with BAME elders, and community groups that are supporting them, to co-design the services that they need and deserve.

Maqsood Ahmad
Senior Manager, Strategic Clinical Networks
Greater Manchester Health & Social Care Partnership
Executive summary

This report draws together existing Census and survey data, and original data gathered through a series of focus groups, to explore older BAME people’s experiences of health and social care in Greater Manchester.

Previous research on health and social care suggests that a range of barriers exist which prevent people from BAME backgrounds from accessing adequate services and support. Furthermore, cultural and structural changes mean that the care needs of older BAME people are rapidly changing. Yet existing research on the topic of ageing tends to neglect the experiences of older BAME people in particular. Given the significant increase and projected growth of Greater Manchester’s older BAME population, this report highlights the importance of older BAME people’s experiences in addressing current gaps in health and social care provision in the area.

Reflecting absences in the academic and policy literature, a review of existing Census and survey material reveals a lack of sufficient quantitative data in regards to the specific experiences of older BAME people. The limited data that does exist suggests that older BAME people living in Greater Manchester experience a poorer level of care compared to their white counterparts, and points to potentially unmet needs amongst the older BAME population. The report builds on such findings with material from focus groups to provide a fuller picture of what these unmet needs might be and how they might be best addressed.

Focus groups were conducted in the three Greater Manchester boroughs of Manchester, Bolton and Oldham, and addressed a number of key questions relating to the needs and experiences of older BAME people in health and social care settings. Findings from focus groups reveal an overall picture of a lack of confidence and satisfaction in health and social care services, and point to a number of areas where needs are not being adequately met. The analysis outlines three key areas where focus group participants describe experiencing a lack of dignity. Issues around communication and decision-making, bodily integrity, and complaints procedures are characterised by unequal and unfair treatment, degrading the dignity of older BAME people and contributing to a particular ‘racialised’ experience for older BAME people in health and social care settings in Greater Manchester.

The report concludes with a number of policy recommendations that must be urgently attended to if the needs of older BAME people in Greater Manchester are to be adequately met and inequalities in health and social care properly tackled. In particular, the report highlights the lack of consideration for the needs of BAME older people and a failure to recognise stark ethnic inequalities in both the primary care strategy and public health plan. It is argued that what is needed is a significant culture shift within the health and social care sector in Greater Manchester, including at senior management level as well as a commitment to support, through resources and finances, the work of BAME community and voluntary organisations who currently fill substantial gaps in provision.
1. Introduction

There is considerable evidence that health inequalities persist for people from BAME groups. Yet, still little is known about older BAME people more specifically.

This report draws on Census and survey data and the experiences of older BAME people living in Greater Manchester, gathered through a series of focus groups. It reveals key areas of concern in relation to older BAME people’s interactions in health and social care settings and the role of discrimination based on racial and ethnic differences. In particular it highlights how these interactions, often characterised by a lack of respect, unequal treatment and inadequate and inappropriate levels of communication, result in a loss of dignity and dissatisfaction with current practice.

The issues raised in this report will be of increasing concern because it is estimated that by 2026 there will be over 1.3 million people from BAME backgrounds aged 65 and over living in England and Wales (Buckner et al. 2011). In Greater Manchester the BAME population grew by 80% from 2001 to 2011 (according to Census data, 2011). And, Manchester is now rated as more diverse than London in the sense that no one ethnic group exceeds 10% of the total population (ONS, 2011). The city of Manchester also has one of the largest older BAME populations in the UK with 23% of older people reporting that they were born outside of the UK (Manchester Health and Care Commissioning, 2017). This recent, as well as further expected future, growth in the number of older people from minority ethnic backgrounds calls for the need to recognise, uncover, and understand the diverse and heterogeneous nature of old age and later life experiences and needs within different ethnic groups (Zubair & Norris, 2015). In particular, such demographic changes may have a number of important housing, health, and social care implications which may challenge existing research, public policy, and infrastructure planning (Boden & Rees, 2010).

Research and policy on ageing has, to date, largely ignored ethnicity, and this suggests that there is also a potential shortfall in the current and future provision of health and social care for older BAME populations. Manchester City Council’s strategy for ageing (Manchester Health and Care Commissioning, 2017) acknowledges ethnic inequalities but these ideas are not mainstreamed in broader health strategies in Manchester and Greater Manchester. Following devolution, Greater Manchester’s Health and Social Care Partnership has committed to improving population health. The ‘Population Health Plan: 2017-2021’ (GMHSC, 2017) and the Primary Care Strategy (GMHSC, 2016) emphasises the need for a ‘proactive’ person and community-centred approach to health. Yet, whilst poverty and the ageing population are key areas of focus, notably missing from the plan is the inclusion of ethnic minorities as a group that requires specific attention. However, there is growing evidence that ethnic differences can influence patterns of illness, healthcare seeking behaviour, the use of healthcare services and experiences of care. Ethnic inequalities persist both in relation to over-representation in low-income households and high unemployment, but also in terms of uneven access to health and social services and experiences of treatment and care.

This report begins with a summary of what we already know, in terms of persistent health inequalities and disparities in uptake and access to health and social care services. We then
detail the aims and methods used for the research presented in the remainder of the report. The results of Census and survey analysis are presented to highlight the potential extent of current and projected need for health and social care among older BAME people living in Greater Manchester. The experiences of older BAME people are then discussed in relation to four key areas: issues of poor or inadequate communication, absence of respect for personal and bodily integrity, unequal treatment and the challenges involved in making a complaint. Finally, the last section outlines key areas that emerge from the research that relate to current policy approaches and offers recommendations for ways forward.

1.1 Older BAME populations, health & social disadvantage
Evidence suggests that certain BAME populations in the UK are more likely to have poorer health, particularly in later life, compared to the White British population. For example, 70% of Pakistani, Bangladeshi, and White Gypsy or Irish Traveller women aged 65 and over reported having a limiting long-term illness compared to 56% of all women; similarly, 69% of Bangladeshi and White Gypsy or Irish Traveller older men reported being ill compared to 50% of all men (Bécares, 2013). Furthermore, the average ‘disability-free’ life expectancy in BAME populations in the UK is significantly lower than in White populations and can be as low as 50 years old in some ethnic groups (Bécares, 2013; Jagger, 2015).

Health inequalities have been associated with a lifetime experience of socioeconomic disadvantage, which occurs disproportionately in ethnic minority groups (Nazroo, 2003). For example, over half of Bangladeshi and Pakistani older people and over a quarter of Black Caribbean older people live under the poverty line compared to 20% of White British older people (Age UK, 2013). Furthermore, someone from a BAME background is seven times more likely to live in an urban area, a higher proportion of which are deprived, than someone who is White (Sunak & Rajeswaran, 2014). However, a recent study found that older people from ethnic minority backgrounds report poorer health outcomes even after controlling for social and economic disadvantages (Evandrou et al., 2016). This suggests that BAME individuals are more likely to age prematurely and develop age-associated illnesses and diseases at a younger than average age regardless of their socioeconomic background (Evandrou et al., 2016).

An explanation for such pronounced ethnic health inequalities in later life may be the low uptake of health and social care services throughout the life-course among BAME groups. According to a recent report, as many as 48% of older BAME people surveyed in Manchester did not take up free NHS health checks to which they were entitled and of that group, a third did not know such checks existed (Patnaik and Miller, 2017). There is also low uptake across the different modes through which social care is delivered, that is: unpaid carers; social service provision of social care; and self-funded care. Despite stereotypes that BAME individuals are more likely to ‘look after their own’, the 2011 Census reported that BAME individuals are significantly less likely to report being unpaid carers than White British individuals. This may be related to BAME individuals’ perceptions of a carer role as it is often seen as an extension of an existing responsibility rather than informal adult care (Johl et al.,
1.2 Understanding low uptake of services amongst the BAME population

Research has found that BAME people experience more barriers when accessing health and social care services compared to White majority groups. Barriers include, although are not limited to: discriminatory practices including fear of racism and discrimination; unfamiliarity with the UK system; lack of knowledge and communication (patients and professionals); mistrust; religious and family issues; stigma; previous negative care experiences such as experiencing a lack of cultural awareness; and a lack of language-matched or culturally sensitive information and services. Many of those barriers are unique to BAME groups and prevent or discourage BAME individuals from accessing health and social care services. Avoiding the use of health and social care services throughout the life-course could potentially lead to more serious health problems in later life, which may, to some extent, explain ethnic health inequalities in old age.

Secondly, in addition to disparities in accessing health and social care services, BAME individuals are also more likely to have unmet needs when using services. This also relates to the barriers experienced by BAME individuals. For example, an individual who has limited English proficiency may require translation and interpreting resources or advocates, yet this is often not provided. Family members or friends are commonly used as interpreters and this poses issues of confidentiality and risks of information being filtered either deliberately or because the family member, carer, or friend cannot interpret accurately. This is especially relevant in situations that might give rise to embarrassment or which run counter to cultural norms (Robinson, 2010). This may result in the patient not being fully aware of their health condition or not receiving the treatment that they desire. Research has also found that, generally, ethnic minority individuals are less satisfied with health and social care services and have a lesser understanding of the UK health and social care systems (Greenwood et al., 2016; Willis et al., 2012).

Thirdly, assumptions made by patients and service providers may prevent BAME people from accessing health and social care services. It has been found that BAME individuals often do not perceive health and social care services as available or accessible, which may be due to having negative previous experiences (Greenwood et al., 2016). In addition, service providers often assume that family prefer to provide care in BAME networks (Calanzani et al., 2013). For example, research has found that general practitioners (GPs) are less likely to refer minority ethnic patients to relevant agencies such as housing or social care services (Bowes, 2006; Manthorpe and Stevens, 2009). Furthermore, studies of BAME carers found that Indian carers were more likely to report that their social worker did not check up on them because of the assumption of extended family care (Hubert, 2006). This suggests that current care provision for older BAME populations, particularly South Asian older people, is organised based on a set of assumptions and generalisations about cultural identities, family networks, and the role of women primarily as carers. However, evidence suggests that whilst this may
have been the case in the past, needs are rapidly changing. Changes to household composition, including smaller homes that make extended households and at-home care for older residents less feasible, mean that other forms of provision are increasingly sought. In addition, recent research challenges the assumption of women and work by illustrating how, whilst BAME women are less likely to be employed for a number of reasons, including due to discriminatory practices (Nazroo and Kapadia, 2013) that does not necessarily mean that they are not looking for work, nor that they would prefer to be full-time carers. This emphasises the need to address such assumptions made by both individuals and service providers so that access to health and social care services can be improved among BAME groups.

2. Aims and approach of this study
The aim of this report is to fill the gap in knowledge on older BAME people’s experience of health and social care in order to feed into public debate and policy on health and social care in Greater Manchester. The research set out to address the following key questions:

- To what extent are current and projected levels of need in relation to health and social care being met for older BAME people in Greater Manchester?
- Are BAME older people satisfied with their experiences of health and social care services?
- To what extent do older BAME people feel listened to and supported in professional health and social care settings?

To address these questions, the study has used a mixed-methods approach to examine whether the current health and social care provision for older BAME people in Greater Manchester is adequate. This approach is comprised of two core elements. First, Census and survey data was analysed to assess the level of satisfaction with services. Second, focus groups were conducted in order to explore in greater depth older BAME people’s experiences with health and social care services in Greater Manchester.

2.1 Census and survey data
The first element of this project began by conducting a scoping of data available regarding satisfaction with health and social care of older BAME people, both nationally and in the Greater Manchester area. A small number of sources were found that appeared to provide data related to this. These were: the NHS GP Patient Survey, the CQC Adult Inpatient Survey, the BHA Manchester BAME Patient Experience Survey, the National Survey of Bereaved People (VOICES), the N8 Research Partnership projection data on demographic change in the North of England, Understanding Society, and the UK Census. Unfortunately, the BHA does not make its BAME Patient Experience Survey data available to researchers, meaning that only overall percentages reported by the BHA (Patnaik and Miller, 2017) could be used and no analysis could be conducted for the older cohort in this survey. Similarly, for the Adult Inpatient Survey and VOICES, as these only included a small number of BAME respondents,
data on ethnicity had been removed before the data was made available. The CQC reported on some differences in their results between ethnic groups, and although these do not concern the older age group specifically, they are integrated into the quantitative section of this report where appropriate. The same has been done with relevant projections from the N8 Research Partnership. We could find no existing reports of analysis of Understanding Society data on health and social care provision for older BAME groups, and unfortunately conducting robust statistical analysis on this complex data set was beyond the capacity of the resources available for this small-scale project.

This left our project with only two sources for secondary data analysis: the NHS GP Patient Survey (NHS England 2018a), and the Census. The GP Patient Survey data broken down by ethnic group was obtained from the survey’s website (www.gp-patient.co.uk) for questions 26a-c and 28-31, for Manchester CCG, Bolton CCG, Oldham CCG, and on the national level. Responses for relevant ethnic groups were compared to the ‘English/Welsh/Scottish/Northern Irish/British’ group and the differences tested for significance. Census data was obtained from the UK Data Service website’s InFuse interface (infuse.ukdataservice.ac.uk) for 2011 and 2001 and from the service’s Casweb interface (casweb.ukdataservice.ac.uk) for 1991 data. Data was obtained and analysed on the national level, and for the Greater Manchester, Manchester City, Bolton and Oldham areas. The three boroughs were chosen because they have high proportions of older BAME populations relative to other parts of Greater Manchester. The analysis centred on an aggregate of all ethnic minority populations and, where possible, specific minority groups, which make up the largest older ethnic minority populations in Greater Manchester.

The age ranges used in this analysis vary due to the ranges available. The N8 Research Partnership, for example, only make data for older people aged 75+ years available. In most other analyses we have used the range 65+ years, except in instances where it is useful to capture the growing population of older ethnic minorities aged 50+.

2.2 Focus groups
A major limitation of previous research exploring older BAME people’s usage and experience of health and social care services is that many of the studies have relied on large-scale quantitative surveys and therefore there is a lack of qualitative research. This suggests that personal experiences of older people, in particular those from marginalised groups, have largely been absent in the literature and therefore in policy.

Focus groups were conducted in three Greater Manchester boroughs with relatively high proportions of older BAME populations, as compared to GM as a whole: Bolton, Manchester City and Oldham. The key purpose of the focus groups was to explore the experiences of health and social care among older BAME individuals. The discussions were structured around two key themes: the level of care that people currently receive and whether people felt that they were listened to by healthcare professionals in relation to getting adequate support and information.
Focus groups were organised with the help of the North Manchester Black Health Forum in Cheetham Hill, the Asian Elders Resource Centre in Bolton and the Indian Association in Oldham. The intention was to limit the number of participants in each focus group to ten to enable quality discussion and give everyone the opportunity to speak. However, all of the focus groups attracted a far greater number, which was an indication of the intensity of interest in discussing these matters. The group in Cheetham Hill attracted the highest number, with approximately 25 participants. In addition, we received a message from a man who had been very keen to attend but had not been able to due to an extended stay in hospital, outlining some of his experiences. In Bolton 15 people attended, and in Oldham 12. The majority of participants were aged over 65 years with the exception of two carers who attended with relatives and also contributed to the discussion. It is also worth noting that many of the participants were in the joint role of being carer and cared for; sometimes caring for partners, children or grandchildren and friends.

In terms of the ethnicity of participants, the vast majority from all three groups were from South Asian backgrounds. In the Cheetham Hill group there was greater diversity, the second largest group being of Black Caribbean background. Given the limited resources for this project it was not possible to extend the study. We would suggest that an extended study should involve a more diverse sample, including more Black Caribbean and Chinese older people, to better reflect the diversity of the population in GM. The majority of participants spoke English fluently or to a level high enough to participate. However, in all groups an interpreter was provided in order that all members could fully participate and opportunities were given to include as many people’s experiences in the discussion as possible. The two researchers also spent over an hour with each of the focus groups after it concluded, during which time it was possible for participants who may have been reticent to disclose information in the group setting, or who did not get a chance to speak given the number of participants, to share their experiences.

It is important to note that the discussion was left broadly open to ‘healthcare’ in general, as in practice people experience different settings on a continuum and thus do not always make distinctions between different healthcare settings, nor between aspects of social care. For example, a referral from their GP may result in a hospital visit or stay, which may then generate a social care intervention.

3. The growing needs of older BAME people in Greater Manchester

In this section we outline the quantitative evidence available regarding the growing health and social care needs of older BAME people in Greater Manchester. The discussion integrates available data on health and social care for older BAME people in Manchester, Oldham, Bolton, and nationally, with secondary data analysis of the NHS GP Patient Survey and the UK Census. In particular, it focuses on those in four minority ethnic groups: Indian, Pakistani, Chinese, and Black Caribbean, which are identified as the groups in Greater Manchester with the largest proportion of older people. Unfortunately, due to the limited availability of
quantitative data in this area, this study is not able to provide a decisive picture of the ability of health and social care provision in Manchester, Oldham and Bolton to meet the needs of older BAME residents. However, the findings below provide some background on this issue.

The population of BAME people, and older BAME people in this area has grown significantly over the last two decades, and is predicted to continue to increase. While the 2001 Census counted 299,232 residents of Greater Manchester not identifying as White British, by 2011 this number had increased to 540,841. This equates to an increase in the proportion of those who did not identify as White British from 12.1% to 20.2% between 2001 and 2011. During the same period, the number of White British residents of greater Manchester decreased from 2.18 million to 2.14 million. In terms of the older age group, 62,859 non-White British residents over 50 years of age were counted in Greater Manchester in the 1991 Census, while in 2011 this group numbered 87,302. Census data on increases in the number of Indian, Pakistani, Black Caribbean, and Chinese residents over 50 years of age in Greater Manchester is given in Figure 1. Each of these ethnic groups has seen an increase decade on decade in residents over 50 years of age in each of the four geographical areas, with the exception of Black Caribbean residents in Bolton who despite increasing more than three-fold between 1991 and 2001 have since seen a 28% reduction. In particular, Pakistani residents over 50 more than doubled in each of the geographical areas since 2001, and numbered 16,528 in Greater Manchester in 2011. Bolton is home to a larger proportion of Indian residents than other areas, and the 50+ group in this area also saw a 91% increase from 2,403 in 2001 to 4,583 in 2011.

Based on Census figures, the N8 Research Partnership reported projections of demographic change in the functional economies of the North of England in their Final Report, Strand 4 (Buckner et al. 2011). They predict that the population of BAME residents in Greater Manchester will increase to 380,000 in 2036, and that the population of BAME residents over 75 years of age will increase from the 6,100 counted in 2011 to 15,768 in 2036 (See Figure 2).

---

1 The report uses the age group of 75+ years.
When considering the needs of these groups in terms of health and social care, language service provision is one area that is becoming increasingly important. According to the Census, 4.4% of all those over 50 living in Greater Manchester in 2011 (or 37,102 people) did not have English as their main language, and almost half of these residents (16,503 people) could not speak English well or at all. Although this represents a small proportion of the total population of this age group (around 1.9%), it constitutes a large number in absolute terms who may require assistance in communication and understanding when they access NHS and social care services. The proportions of those over 50 who could not speak English well or at all in Manchester City, Bolton and Oldham were 4.3% (4,663 residents), 2.9% (2,627) and 3.7% (2,657), respectively. It goes without saying that much of adequate health and social care provision rests on the patients’/clients’ ability to understand both the services available to them and the information provided to them in their interactions with professionals, and these figures illustrate the demand for translated materials, interpreting support and other language services in the provision of health and social care to this older group of BAME residents.

The N8 Research Partnership has also projected that these areas will see considerable increases by 2036 in the number of over 75s who have self-reported health that is ‘not good’ as well as the number with a limiting long-term illness (see Figure 3). Although these projections are for all ethnic groups in the population, given predicted increases in the number of BAME residents and older BAME residents, it can be assumed that the BAME group will see similarly large increases here.

In terms of social care need in particular, considerable numbers of older residents (of all ethnicities) in Manchester, Bolton and Oldham areas report needing assistance at home. The number of over 65s in these areas who reported being unable to manage at least one domestic task or self-care activity in 2011, and the projected increase in this number by 2036 is given in Figure 4. Bolton in particular is predicted to see large increases in this need, with a 72% increase predicted in those unable to perform a domestic task, and 71% increase in those unable to manage at least one self-care activity. Another potential indicator of the extent of need for social care is the number of people providing unpaid care. Although it is important to bear in mind that understanding of the meaning of ‘unpaid care’ may vary among survey respondents, and there is no indication of whether this care is being provided to elderly parents, other family members, or someone outside the family unit, figures available from the Census indicate that there are sizable cohorts of BAME residents in Greater Manchester providing unpaid care. The Pakistani group is particularly large, with 12,151 people in 2011 reporting that they provide some form of unpaid care (compared with 5,251 Indian residents, 1,917 Black Caribbean residents, and 1,426 Chinese residents). Furthermore, these figures are predicted to increase for the wider BAME cohort, from 24,000 in 2011 to 35,000 in 2036 (Buckner et al. 2011).

---

2 The report does not provide data on this for an over 50 age group.
Figure 3

Projected change in population aged 75+ living with a limiting long-term illness (all ethnicities), Greater Manchester

- Other areas
- Oldham
- Bolton
- Manchester

2011:
- Other areas: 99,000
- Oldham: 8,200
- Bolton: 16,000
- Manchester: 19,800

2036:
- Other areas: 177,900
- Oldham: 13,000
- Bolton: 30,100
- Manchester: 34,000

Figure 4
3.1 Are needs being met?

Given the above indications of the extent of health and social care need for these BAME groups in Manchester, Bolton and Oldham, to what extent are these needs being met? Unfortunately, sample sizes of older persons in the ethnic minority groups in question (Indian, Pakistani, Black Caribbean and Chinese) in the NHS GP Patient Survey were too small at the Bolton, Oldham, and Manchester CCG levels to be analysed. At the national level, although the survey found relatively high rates of satisfaction with care among the over 55 group\(^3\), significant differences in responses to questions about satisfaction were found between each of the groups and the ‘English/Welsh/Scottish/Northern Irish/British’ group (see Figure 4). In addition, each of the Indian, Pakistani, Chinese and Caribbean groups reported significantly lower positive responses to each of the questions relating to their satisfaction with care: whether or not they were given enough time at their last GP appointment, how well they were listened to, whether their healthcare professional was good at treating them with concern, whether they were involved as much as they would like in decisions about their care and treatment, the trust they had in the healthcare professional they saw or spoke to, whether their needs were met at their last appointment, and how they would describe their experience of their GP. It was particularly notable that only 77% of Pakistani respondents in the over 55 group said that they would describe their experience of their GP practice as very good or fairly good, compared with 90% of the ‘English/Welsh/Scottish/Northern Irish/British’ group.

While the above survey covers only healthcare provision at GP surgeries, a separate survey is conducted at national level by the Care Quality Commission (CQC) with regard to inpatient

---

\(^3\) Survey data used to incorporate all adults aged over 55 years.
care. Survey response data is not available to researchers for particular ethnic groups. However, the CQC’s report on the latest wave of data (CQC, 2018) gives a brief overview of findings related to ethnic differences. This includes that ‘Asian or Asian British’ patients reported a below average overall experience of care, as well as below average satisfaction with coordination and integration, and food choice. Furthermore, responses from the ‘Black or Black British’ group indicated that they had relatively more negative experiences in terms of respect for patient-centred values, preferences and needs, and confidence and trust in healthcare staff (Care Quality Commission, 2018).

A BAME patient engagement project was commissioned and published in 2017 by Manchester Health and Care Commissioning to BHA’s Manchester Race and Health Service, and this project was designed to cover GP surgeries, dental practices, community health services and NHS hospital trusts (Patnaik and Miller, 2017). Data from the questionnaire survey administered were not available to researchers, and are not reported by age or in comparison with the views of non-BAME patients. However, they do provide insight into satisfaction with this broader range of healthcare services in Manchester City. In this survey, about 80% (n=458) of respondents said that their overall experience of care was good or very good, and 81% (467) strongly agreed that they were treated with dignity and respect by NHS staff. However, 10% (56) disagreed or strongly disagreed with the latter, and 24% (133) felt that their care was affected by NHS staff’s perception of their nationality, language, skin colour or faith. Of the 8% or 45 respondents who reported requiring the services of an interpreter, 14% (6) said they found it difficult to do so, and 9% (4) said that they had not been able to get one. Importantly, while 75% (289) of respondents said they would feel comfortable making a complaint, a significant proportion, 28% (149), said they had not known that they could do so.

The above figures indicate the potential extent of the current and projected need for health and social care among older BAME residents of Manchester City, Bolton and Oldham, based on growing numbers of older ethnic minority residents in these communities, and growing numbers of those requiring health and social care in general. Existing survey data described above also indicate differences in satisfaction levels for these groups, pointing to potentially unmet needs. However, the figures represent the limited amount of quantitative data available on this topic. This analysis was not able to definitively answer the question of whether or not the health and (particularly) social care needs of older BAME residents in these specific communities were being met. Hence, this project has collected its own qualitative data through focus groups of these residents themselves.

4. Experiences of health and social care: an older BAME perspective

This section discusses the findings that emerged from the focus groups. It highlights how, for many of the participants, experiences of health and social care were simply not adequate. In several cases, deeply distressing examples were disclosed. Unfortunately, these were not exceptional cases, revealing a system that leaves many older BAME people vulnerable to
inadequate and unequal treatment. Whilst many of these experiences may be shared by older people more generally, the following discussion illustrates how discrimination based on racial and ethnic differences often plays a central role in shaping interactions in healthcare settings and affects people’s overall experiences. The discussion is structured around four key areas but it is important to stress that, although we discuss them separately, these issues overlap and are often mutually constitutive. For example, not being given adequate information or not being included in decision-making also has an effect on how an individual’s bodily integrity is respected, and so on.

The key overarching theme that connects each of the four themes presented below is that of dignity and respect. Dignity in the context of care provision has been defined in various ways. And, whilst it is a subjective phenomenon and can mean different things to different people, there are certain common threads that we can use to develop a working definition. A sense of dignity is ‘rooted in perceptions of being treated and regarded as important and valuable in relation to others, and, moreover shaped by the wider social and cultural contexts in which care-related interaction takes place’ (Saltus and Pithara, 2014: 22). Dignity is generated in social interactions and is identified through the qualities of respect and recognition of individual and collective worth and value (Jacobson, 2009). It is therefore of particular significance when thinking through interactions and communications with health professionals and associated staff. Often, as others have noted, it is the absence of these qualities that point to its importance as a fundamental human right. Dignity was a term used by participants themselves, and it was the absence of dignity that was repeatedly emphasised by the older BAME people in the focus groups. The importance of dignity in health and social care has been raised by various scholars (see, for example, Saltus and Pithara, 2014; Saltus and Pithara, 2015; Jacelon et al., 2004; Nordenfelt and Edgar, 2005) and has been found to have particular salience in the context of ageing because of the vulnerabilities often experienced by older people. This report highlights how there is a compounding effect for older BAME people. This group of people face multiple disadvantages: issues associated with old age, such as frailty and ill health, combine with structural and everyday racism, which in turn are related to higher rates of unemployment, deprivation and poorer housing (Nazroo, 2003) to make older BAME people particularly vulnerable to the issues highlighted below.

4.1 Unequal Treatment

- Many older BAME people feel directly discriminated against because of their ethnic or cultural background.
- Experiences of discrimination tend to relate to public spaces in healthcare settings, such as waiting rooms and hospital wards.
- Experiences of unequal treatment intersect with other issues highlighted in this report, and contribute to a particular racialised experience of health and social care as an older adult.
As highlighted in Section 1.2, older BAME people face multiple barriers in accessing health and social care services compared to their white counterparts. While some of these barriers are due to wider structural issues, research has shown that fear of racism and discrimination is a major contributing factor. Reflecting these trends, this section of the report addresses the various experiences of unequal or unfair treatment that focus group participants felt were related to their ethnic or cultural background. Sections 4.2 - 4.4 of the report highlight how experiences of discrimination are compounded by more hidden ‘layers’ of indignity that older BAME people are exposed to, and explore the ways in which this contributes to a particular experience of health and social care for older BAME people in Greater Manchester.

A number of accounts by participants emerged in response to being asked directly whether they had felt that they had ever been treated unfairly because of their cultural or ethnic background. There were significant differences between focus groups, with some appearing much more reluctant to share experiences of discrimination than others. A reluctance to report racism and discrimination does not mean it does not exist. Reticence to talk about personal experiences of racism may be due to feelings of shame or embarrassment, not wanting to be seen as a victim, desire to fit in or even fear of further repercussions (Harries, 2017). It is also worth noting that, as one community worker highlighted later, many of the older BAME people we spoke to would have migrated to the UK in the 1970s at a point of heightened racism and when there was less sympathy to challenging racism. These issues are also salient to the discussion in Section 4.4, which outlines some of the consequences of complaining for particular groups.

Of the three focus groups, participants in the Bolton group were particularly vocal about their experiences in hospitals. One explanation for why this group were more vocal might be that one member of the group acts as a volunteer advocate for other patients and was therefore more knowledgeable about the institutional structures through which to lodge complaints. Participants in this focus group were from south Asian backgrounds, and shared reports of feeling ignored by (white) nurses on hospital wards, while seeing the same nurses responding to others:

- P1: In a hospital... because if you say 'oh I want this', they ignore it and go away, yeah? And we are waiting and waiting...
- P2: In the hospital, right, it's like, something happened, some time ago, this is when my mum was in hospital. My mum was asking something, 'can you get this', right. Same nurse, but then she went away but she didn't get it. And then another person asked her something, [the nurse responds] straight away...
- P3: Yeah, straight away. So you know, we are waiting for hours.

This anecdote highlights older BAME peoples’ experiences of feeling routinely ignored in healthcare settings, even when explicitly asking for something, which is a theme explored further in Section 4.2. Furthermore, the example above demonstrates how unequal treatment can intersect with the right to bodily integrity (see Section 4.3); restrictions on
bodily integrity are an inevitable consequence of being hospitalised, but inadequate responses to requests for help from older BAME people makes them particularly vulnerable.

Reflecting a similar theme of preferential treatment for others, one of the same group of participants also felt that white patients were seen quicker at their local doctor’s surgery:

Sometimes I feel, when I’m going to the doctor’s surgery, my appointment time is say, quarter to eleven, for example. And I’m there, present. And then someone walks in about, you know, like eleven o’clock. And then suddenly he walks in and he’s gone in! And you’ve been there fifteen minutes earlier to make sure that you’re not late for your appointment... and these guys are white people.

A number of participants explained that they had a similar experience in A&E waiting rooms, and that when challenged, staff would use the ‘excuse’ of prioritising urgent cases. Whilst it is possible that on occasion this may have been the case, it is nevertheless pertinent that the older BAME people felt this way as it is indicative of their racialised experience more broadly. Experiences of racist discrimination are humiliating at any time, but there is perhaps something significant in the public nature of discrimination on a hospital ward, or a waiting room, combined with the vulnerability of being a patient in the first place, which makes these experiences particularly distressing and in need of urgent attention.

4.2 Communication and decision making

- Participants describe experiences of healthcare professionals failing to explain issues properly, or not listening to them, therefore preventing full patient participation in decision-making processes.
- Participants point to an expectation of self-reliance in health and social care settings, leaving them reliant on family members, friends, and local community groups for accessing information relevant to their care needs.
- Negative experiences around communication combine with other issues specific to BAME individuals (such as language), to contribute to an overall experience of health and social care that is significantly shaped by ethnicity.

Participation in decision-making has been identified as an important part of fostering a sense of dignity in health and social care settings, and effective communication is, in this sense, paramount. Two-way communication is central to interactions with healthcare professionals and related staff in healthcare settings, including administrators and receptionists. As discussed above, previous research highlights how examining interactions within healthcare settings can prove vital for revealing unequal and discriminatory treatment, which can in turn go some way to explain inequality in health outcomes. This section sets out some of the context of those interactions before we examine the impact of discrimination and unequal treatment later in the report.
We start the discussion by exploring the range of challenges that participants reported around the theme of communication and decision-making. We emphasise how a lack of information conveyed to individuals by healthcare professionals not only left them feeling excluded from vital decisions about their own healthcare but also conveyed the sense that they were not considered to be of sufficient value to be consulted in this decision-making process. Furthermore, a number of individuals reported that when they tried to explain symptoms to healthcare professionals, or convey a particular problem, they were not taken seriously. We then go on to reflect on how these themes fit with the growing emphasis in public health and health policy on individualised healthcare and the onus on improving patient involvement and patient ‘responsibility’.

The fundamental issue highlighted by many participants is that they did not know what was happening in terms of their own treatment because they were left out of planning and given little information relating to their own health. Consequently, they were unsure as to the precise nature of their diagnosis and treatment plan. Several participants, for example, explained how they were on one medication that was then changed with no explanation as to why. This led to a great deal of frustration, as explained here:

[She] is still managing, but what she said is when she goes to the doctor’s... she doesn’t feel heard. All it is, is just before she can even speak, he sort of gives her ‘well try this medication, well try that medication’. She doesn’t feel heard.

(Cheetham Hill focus group – translation by staff member)

Similarly, a participant from the Bolton focus group described how a doctor had changed her husband’s medication – which he was taking for depression without informing her or her husband. It was only when she collected the prescription from the pharmacy that she discovered the medication had changed. Furthermore, the correct dosage for this new medication was not explained to her or her husband, so she was forced to research this herself.

At other times participants reported feeling frustrated when doctors failed to provide enough information for them to care for themselves properly and, as the following from the Bolton focus group demonstrates, this has consequences for how likely individuals are to seek out help from healthcare professionals in the future:

P4: One time, I went [to the doctor’s] for my diabetes... I says how is my diabetes, they says [in raised voice] ‘is everything alright? OK. No problem’. I said, I’m going mad, why don’t you tell me? If I don’t know anything, so how can I control my diabetes?

BH: So they just didn’t tell you the information you needed?

P4: No. No. I’m not going [to] that doctor now, up to now... another doctor I’m going [to] [...] I say I don’t want that doctor. No see. Because whenever I see that doctor I go mad.
While some participants’ frustrations came from medical professionals withholding important information relating to their health, others felt that they were not properly listened to when reporting particular issues. For instance, one participant recounted the doctor’s reaction when she reported that she had found bruising on her body following a trial of new medication. In this example, the individual felt the need to assert the importance of her own personal knowledge in the face of indifference from the doctor:

So she says she’s been taking medication... she’s been on a medication which finished yesterday and she’s got like bruises [...] so she went to doctors and said ‘why are there bruises here?’, they said ‘well I don’t know’, so she said well if you don’t know, why you sat here for, why you a doctor? So she said I know, it’s my body, so I know that I have taken medication and this [the bruising] is probably from that. (Cheetham Hill focus group – translation by staff member)

Crucially, the withholding of information by doctors – and the lack of willingness to engage with patients’ own knowledge, concerns and experience – undermines these individuals’ ability to manage their own health, and prevents patients being included in decision-making processes. This is particularly relevant in the context of Greater Manchester, since one of the aims of the Greater Manchester Primary Care Strategy is to improve ‘health literacy’ and empower individuals to manage their own health, by ensuring that people living in the region ‘will have the information they need to prevent ill health, manage any conditions and access the right support in their local neighbourhood when they need it’ (GMHSC, 2016: 16). In contrast to the vision laid out in the Primary Care Strategy, the participant quoted previously suggested that the lack of information that this particular doctor provided was ‘maddening’. This was not an exceptional case. Indeed, the experience of not receiving adequate information might be seen as a more general issue, but it is the cumulative effect of a range of experiences that make them particularly salient for older BAME people in these settings.

For example, how patients respond to these sorts of experiences must be understood in relation to the consequences of complaining as an older person from a minority or migrant background, which is explored later in this report.

Given the levels of English fluency among older BAME people in Greater Manchester it is perhaps unsurprising that language was raised as an issue on several occasions. For example, participants in the Oldham focus group highlighted a lack of provision for Gujarati speakers in relation to hospital signage, explaining that signs were often translated into Urdu and Bengali, but rarely Gujarati. There were also reports from focus groups that interpreters were not always provided when they should have been even though guidance for commissioners on interpreting and translation services clearly states that,

‘Patients should be able to access primary care services in a way that ensures their language and communication requirements do not prevent them receiving the same quality of healthcare as others’ (NHS England, 2018b).

It is important to place the role of language alongside other issues of communication and knowledge sharing. Whilst interpreting and translation are important issues there is also a more general need for more tolerance and more attentiveness, amongst health professionals
and related staff, to those with accents and those with English as a second language. This is highlighted by one woman who explained how a male friend, who is fluent in English but has a Jamaican accent, does not feel listened to because of his accent. The woman described how hospital staff interpreted his being black and having an accent as threatening, and she describes how he is often labelled a ‘bad patient’. This is a reasonable assumption for her to make given such forms of racialised stereotyping are well-documented in other public settings and institutions (see, for example, Equality and Human Rights Commission, 2010).

One participant who lives on his own and has limited English, described not feeling listened to by his doctor, but had never asked for an interpreter. This stimulated a conversation in the group about who was entitled to interpreters and who was responsible for organising that. Other participants agreed that they had not been asked if they wanted an interpreter. This lively discussion revealed that – more than simply a matter of language provision – there is an expectation that patients have to actively ask for services, which somewhat ironically relies on knowledge of the language and the existence of those services in the first place. One carer from the Cheetham Hill focus group acknowledged that language was a ‘barrier’ for older generations in their interactions with health and social care professionals. However, her description also highlights that inclusion in decision-making relies on more than just a shared language:

I think the issue is, for this generation, not ours. ‘Cause we can speak English, we’ve [not] got that barrier, you know, we can communicate in that sense. But with this generation, what I think it is is, I don't think there's anyone there for them. And, you know the way the law changed, and you know things change for the government and they can apply for disability or they can apply for PIP [personal independence payments]... it's not actually explained properly to these guys. It's explained to us, to explain it to them. They really have a lot of choice in the matter, once we've explained it still. People should be offering it door-to-door, where they come to your door and they're explaining it, sit them down, comfortably, no pressure, you know, and explain the full situation to them.

Again, there is a clear message of self-reliance here, and perhaps this particular expectation can be understood in relation to the idea of ‘active citizenship’. This is an approach that stresses the importance of active participation of citizens in their communities, including in shaping public services (Barnes et al., 2007). However, as the examples above suggest, not everybody is able to participate or be ‘active’ in the same way. This raises questions for who is considered an ‘active’ (i.e. ‘good’) patient or citizen, and equally, who might be marginalised by such an approach. Furthermore, such an approach once again shifts responsibility onto the individual, neglecting the impact of structural barriers to participation.

In the UK we have witnessed a growing policy shift towards the idea that people need to be more self-reliant in relation to their own health. The introduction of Personal Independence Payments (PIP), for example, was intended to make people more ‘responsible’ for the administration of their welfare. The shift to Universal Credit is another prime example of the current government’s attempts to shift responsibility for welfare away from the state and towards the individual. The Universal Credit system was designed to give greater autonomy
to those receiving benefits. However, as reports of increasing poverty and homelessness show, those currently claiming Universal Credit are facing greater precarity and uncertainty (Trussell Trust, 2018; Doward et al, 2018). Delays in payment, which have caused financial hardship for many people, demonstrate how the shift towards self-reliance can in fact be accompanied by a lack of participation in important decisions. We can see a similar logic at play when the burden of seeking adequate healthcare is left to the individual, or, as is often the case, their family members. In Greater Manchester, the Combined Authority’s (GMHSC, 2017) ‘Population health plan: 2017-2021’ includes an understanding that people should be empowered to have ‘a more active role in their own health’ through a person and community-centred approach. And, whilst it is commendable that within this plan the GMHSC recognise that communities can be ‘experts by experience’, there is a pressing need to recognise the barriers to being heard if one is not a community spokesperson, which are additionally compounded for people from BAME backgrounds. Individuals are excluded from decisions concerning their own health or care, as the following examples highlight.

In practice, what is expected of patients is that they need to be very assertive, and ‘speak up’, in healthcare settings if they want to secure the treatment they feel they need, or get adequate answers to questions they might have. This is reflected in survey data, outlined in Section 3.1 of the report, which shows that BAME groups report significantly lower levels of satisfaction regarding their care than their white counterparts. For example, one participant in our focus groups described how she had to go ‘begging’ for home-based care at her local healthcare centre before she was able to secure this kind of support. Other participants were unsure as to whether they were eligible for particular forms of support or services – for instance, disabled parking badges, or pendant alarms – and often these questions were answered in the focus groups themselves by other participants, which highlighted the vital role that community groups play as important (informal) sources of knowledge for these older people. Some participants also described how they relied on younger relatives to accompany them to appointments who would talk to the doctor on their behalf in order to advocate for their needs, but also sometimes to act as an informal translator (see Section 1.2 for the potential problems associated with this). Navigating the bureaucracies of the UK’s health and social care system, including finding out what services are available in the first place, also appeared to require a certain level of confidence and an active seeking out of information which many participants were not able to do without informal support from friends, family, or even staff at the community groups. At times, there was an expectation that participants travelled significant distances for some treatments and services. For example, one woman in the Bolton focus group was repeatedly told to travel to another health centre in the area as there were no nurses available to treat her at her registered GP surgery. She complained that she had ‘had enough’ and was planning on registering elsewhere, despite having been a patient at her current practice for many years. Travelling any distance can be difficult for older people, and especially so if they are without the support of family or friends and/or living in areas with poorly integrated public transport.

Local community groups are crucial for obtaining the knowledge needed to navigate the health and social care system, as well as general information on health and wellbeing. This is often in addition to family members providing information, but for some participants without
family, the local community group can be the only source of help. Community groups host information sessions on issues such as diabetes and dementia, but crucially also provide spaces for informal knowledge sharing between attendees and staff. The latter appears to be particularly important for older people who live on their own, or do not have the support of family in navigating their health and social care needs, and one community group was even described as ‘like a family’. An example of this came from two participants in the Cheetham Hill focus group (a staff member and an attendee of the community group) who described how they were providing support at the time for another member of the group who was in hospital, but had no family. They were visiting him regularly but also trying to secure housing for him in the local area so that he could be closer to his support network. The role of local community groups in knowledge sharing and advocacy for older BAME people is set to be increasingly important as changes in family structures result in more older BAME people living alone. Traditionally, many South Asian older people have lived with family, often in extended family households, throughout older age. However, family structures are adapting to changes in employment patterns and generational shifts in culture. As noted above, these changes are not always recognised. Social care workers, for example, often continue to work with the assumption that care will be provided by extended family networks (Hubert, 2006). Reflecting on these changes, a member of staff at a community group in Oldham explained how they were raising funds to build an assisted living home on the same site as the community centre:

BH: Is there a growing need for that, then [assisted living accommodation]?

P5: Looks like it now. Now. Because obviously people are living there on their own. You know families, like they have sons, daughters, but they with jobs, they have to move. So there will be a need. Like in Leicester and London, they have homes especially for Asian, Indian community I would say, but we haven’t got anything in this area.

BH: So do you think that’s a growing problem because people’s kids are moving away?

P6: That’s right, as well as the kids are being born and brought up here, so the culture is... changing a bit as well, because obviously, whatever they see, and the culture is around them, children are going to be independent, going away as well. So it is, it is going to be a growing concern.

There was also agreement that these changes mean that older people from the local community are increasingly reliant on the services of the community centre, as well as having different housing needs. However, the impact of significant budget cuts to the third sector under austerity means that community groups are struggling to meet current demands. There is growing evidence to show that BAME populations have been disproportionately disadvantaged by austerity and cuts to the third sector (Craig, G and O’Neill, M, 2013; Craig, 2011; ROTA, 2009). Chronic underfunding and the increasing reliance of older BAME people on these services will only add to the pressure on local community groups that are already struggling to survive.
4.3 Bodily Integrity: the right to choice and control

- Reflecting fundamental principles in medical ethics, bodily integrity and the right to choice and control are crucial dimensions of dignity in everyday health and social care settings.
- Participants reported a number of issues that related to intimate bodily experiences, including medical procedures and dietary requirements. These experiences were accompanied by a sense that participants’ bodily integrity had been undermined.
- Historical and ongoing exposure to racism in many areas of life shapes older BAME people’s experiences of bodily integrity, and therefore dignity, in such settings.
- The concept of dehumanisation highlights how experiences around bodily integrity for older BAME people relate to experiences of racism.

This section highlights how a lack of adequate communication can intersect with a sense of bodily integrity, and what this means for feelings of dignity for older BAME people in health and social care settings. Bodily integrity refers to the ability of an individual to have control and choice, and make informed decisions in matters regarding their own body. It also implies the right to demand as well as refuse treatment (Herring and Wall, 2017). Key to ensuring this in a medical context is the principle of gaining informed consent from patients before any medical procedure takes place, as outlined by Beauchamp and Childress (1979) in their principles of biomedical ethics.

A pertinent example of the way in which the right to bodily integrity is not always respected is through taking of blood in hospitals. The issue was raised on numerous occasions and a number of participants described how, when having blood taken at the hospital, they were not explained why this was necessary. Again, communication (or the lack of) was significant. It is notable that several participants explained how, despite repeatedly asking, they were often kept in the dark as to why ‘so much’ blood had to be taken. However, the lack of control over one’s own body and what was being done to it also carried deeper consequences, and participants described being made to feel less than human. For example, one participant described how doctors at his local hospital repeatedly tried and failed to take blood from his wife, who was dying, adding to her discomfort. Clearly distressed by the experience, he related how he had desperately appealed to the nursing staff to stop and asked that they see her and recognise that she, ‘is a human being, not an animal’:

My wife was in hospital, Crumpsall hospital. They taking blood every day, every day. She don’t eat, she said ‘I don’t eat because food is not going down here’. Three weeks [later] she died. So what for they are taking this blood? Three, four bottles every day they’re taking... and one time when nurse coming, she put [it in] again, not successful. I said look, this is a human being, she’s not [an] animal. If you don’t know, you call somebody else, who knows how to take the blood.
When the participant asked the nurse why so much blood was necessary, she simply said that she had received orders from someone else. In the focus group, the participant went on to explain that, following the intervention above, a doctor was summoned to see his wife. This doctor was familiar with his wife, and agreed that these repeated blood tests were indeed unnecessary.

Another participant suggested that the only explanation for so much mystery blood-taking was that hospitals or healthcare professionals were ‘selling’ patients’ blood. Rather than dismiss this as purely conspiratorial, we might reflect on what this reveals about participants’ experiences. Blood-taking is a particularly intimate act; it does not just concern an individual’s body, but the *removing* of something so vital to that person’s body. It is easy to see how a lack of proper explanation in relation to this practice might be experienced as an extractive or exploitative interaction.

Experiences around taking blood point to how a sense of bodily integrity is central to dignity in health and social care settings. In addition to taking blood, participants described a number of other experiences – some more distressing than others – that can be understood in relation to bodily integrity. Again, these intersected with the issue of communication, so that inadequate communication from or between health and social care professionals compounded a lack of bodily integrity around already intrusive procedures. One participant, who was a full-time carer for her mother, recounted how her mother was given a male doctor for an endoscopy procedure, despite making it clear to her GP that her preference was always for a female doctor. The carer and her mother were left wondering why the GP had failed to communicate this preference to the hospital. Highlighting the very personal ramifications of this, the carer emphasised that her mother’s husband of many years had recently died, and that this was significant in how her mother felt about a male doctor performing this intimate procedure:

> I’ve literally had to stop so many procedures from happening with my mum because there’s a male doctor and my mum is not comfortable. My GP knows that, and it should come, ‘cause all these referrals come from my GP, so I don’t understand why my GP is then getting it to a hospital appointment, we’re waiting six to eight weeks for a procedure. Comes to it, we went to Rochdale then Bury, and they were getting male doctors to do an endoscopy, through the back passage. Now, that’s not fair [...] and, you know, especially being married for however many years, my mum lost her husband four years ago. So, my mum has never, ever let another man next to her, and all of a sudden these doctors think it’s alright?

Again, this could reflect the experience of many women, regardless of ethnicity. But, it is the cumulative effect of experiences described throughout this report which bring into focus this particular woman’s minority ethnic background. There is a risk, too, that gendered interactions are interpreted and dismissed as ‘cultural’ issues by healthcare professionals, and therefore not taken seriously.

Food was another concern for a number of participants whose dietary requirements had not been adequately met. One participant complained that her husband, who is a Hindu, had
been given beef when he was in hospital, and that this showed a lack of ‘cultural awareness’, but also of respect. Participants from the Oldham focus group suggested that food was a particular problem they had to deal with in hospital settings. They felt that Muslims were often catered for in terms of Halal options, but that their own dietary requirements as ‘Gujarati vegetarians’ who do not eat fish or eggs, but do eat dairy products, were not considered. As such, participants described how they often had to say they were vegan, which limited their eating options in hospital settings. It would be easy, and perhaps tempting, to frame this issue as one of cultural awareness, as one participant suggested. However, it might be better understood as contributing to a wider framework of dignity, where having choice and control over what you put into your body has as much of an impact on experiences of bodily integrity – and therefore a sense of dignity – as what gets taken out. The neglect of particular groups’ dietary requirements therefore further compounds a lack of dignity for older BAME people in health and social care settings.

What emerges in these accounts and the broader discussion that they generated in the focus groups is that often older BAME people feel that they are treated as less than human. The concept of dehumanisation can be used to describe this experience of being treated as less than, or sub-human. Dehumanising treatment can be understood as any treatment that undermines what we understand as a fundamental human right, including bodily integrity. The previous example of blood-taking demonstrates how consistent dehumanising treatment in the lead-up to an individuals’ death made this participant feel like his wife was treated ‘like an animal’. This sense of dehumanisation articulated by participants is particularly relevant for understanding the experiences of older BAME adults. Many scholars of ‘race’ and racism have theorised the role of dehumanisation in the experiences of racialised people. As Goldberg (2015: 126) notes, ‘racism has always confronted black people first as black, and only secondarily, if at all, as human’. In a political and cultural climate where racism is generally considered unacceptable, this dehumanisation appears in much subtler ways. It is vital that we acknowledge the racialised character of these experiences, in order to address the unequal treatment of older BAME people in health and social care settings.

4.4 Complaints procedures: being or becoming the ‘problem’

- A number of barriers exist that prevent older BAME people from challenging unfair or inadequate treatment in health and social care settings.
- Older BAME people are not always familiar with official channels for complaint, but perhaps more importantly, feel there are consequences to ‘speaking out’ about unfair or inadequate care as an older BAME person.
- Stereotypical understandings of how patients from migrant and minority backgrounds ‘should’ behave in health and social care settings result in discriminatory treatment, and further dissuade older BAME people from challenging unequal or inadequate care.
In this section we consider what happens when older BAME people (or their carers), tired of being treated unfairly, attempt to re-assert control over their own bodies and lives in health and social care settings. How to complain, whether formally through official channels, or informally through publicly expressed grievances, was a significant theme that emerged from the focus groups. Indeed, notably, whether it was even possible to complain was a question that was intensely discussed.

Many participants were not familiar with official complaints procedures; they did not know who to complain to, or how. The Gujarati speakers, for example, when asked whether they had reported the lack of signage or unavailability of Hindu food to anybody, explained that they were not sure who they would speak to, or what avenues were available to give feedback about language provision or food on wards. Notably, the focus groups became the place where some participants found out that lodging a complaint in different healthcare settings was possible. Particularly striking was that few people had any sense that it was possible to complain at the GP’s surgery. For those who did, there was a sense that their complaints would not necessarily be taken seriously, and so filing an official complaint was often considered a waste of time. Sometimes such an assessment was based on personal experience, as one participant in the Bolton focus group recounted: ‘I've made complaint [to the] hospital so many times. They sending letter, “sorry about that”, that's it, nothing else’. Indeed, in the absence of change following complaints, people wondered what the point of complaining was.

Of deep concern is that those who did complain often faced significant consequences. These consequences are particularly relevant for understanding the experiences of older BAME people in health and social care settings. Informal complaining could be met with a disciplinary threat, for example one carer described how, when she is ‘vocal’ about her mother’s care, healthcare professionals ‘bring out’ the zero tolerance policy. Another participant in the Cheetham Hill focus group recounted a similar anecdote, describing how their friend, who is an older Jamaican man, had come to be labelled a ‘bad patient’ at the hospital, even though his frustrations appear to be because of a lack of communication by medical staff:

[He]’s got a very... heavy, still has a very heavy Jamaican accent, he’s very unassuming. Instead of asking the district nurses or the doctors questions, he gets very frustrated and he starts shouting at people, and then he gets the 'bad patient' label. Yeah, because they don’t understand him because he’s talking English but he’s got very strong accent, and because nobody's explaining, it’s only me who went and just said right, went and saw his consultant...

The patient’s ‘heavy Jamaican accent’ means that he is often not understood or listened to and when this failure in communication becomes frustrating he is interpreted as threatening by medical and related staff. There are clear links to be made here with work on Black masculinity, specifically with the pervasive stereotype of the ‘aggressive’ Black man (or, indeed, the ‘angry’ Black woman) (Collins, 2000), which in the case above is used to position the patient as ‘bad’ rather than acknowledging that there is a responsibility to find ways to enable communication. In a similar case, a participant from the Bolton focus group gave the
example of a man she knew who, after complaining about wheelchair accessibility at his local GP practice, was visited by someone from social services. This professional then proceeded to question his mental health and threatened to move him to a care home and have him categorised as ‘mentally disturbed’:

He hasn’t got any access to get in GP’s surgery with the wheelchair, unless somebody lift the wheelchair. So one of his niece explained he can’t get to your surgery, you need four people, so [the doctor] said ‘it’s your problem’, so she said I need a visit at home, he’s not well. So next thing [the doctor] came with a social worker and he said ‘pack all your stuff up, tomorrow morning you are going in a nursing home, you are mentally disturbed’. So nine o’clock at night he’s ringing me, ringing his niece, we went out and we said... so we have to contact out of hours - because I know out of hours social worker - and I say what the hell is going here, can you bring somebody who can assess him, he’s not mentally disturbed, he’s physically, right? You can't drag him out if he don't want to go in the nursing home, and they even told the carers that he was paying not to bother coming next day. We made a strop and it's gone very further now.

Fortunately, in the above situation the man in question knew someone who could advocate on his behalf to prevent any further harm. In both cases, it is clear how the person doing the complaining, or at least expressing dissatisfaction at the care they are receiving, is repositioned as the source of the problem. In the first case, the patient is labelled as ‘bad’, and in the second, as ‘mentally disturbed’. Previous research that examines the impact of race and racism has drawn attention to this phenomenon in work on complaining. Sara Ahmed’s work, for example, provides a useful model for understanding how institutions in general are able to manage and ‘re-direct’ complaints, so that ‘the efforts to stop a complaint include attempts to discredit the complainer [...] a complaint can be redirected to the complainer; as if she says something is wrong because something is wrong with her’, or, in other words, ‘to locate a problem is to become the location of a problem’ (Ahmed, 2017). In this way, the man complaining about accessibility at his GP’s surgery is made the source of the problem; rather than his complaint being taken on board, there is something deemed ‘wrong’ with him. Furthermore, in this particular case, there is the clear threat of serious repercussion, with a seemingly banal complaint having the potential to lead to further loss of personal (bodily) integrity, dignity and even freedom. Moreover, the circulation of stories such as these serve to prevent individuals from ‘speaking out’ or using more formal channels for complaint.

While on the one hand the ‘threat of the other’ might function to stigmatise those who speak out in such settings, we might also consider the notion of a ‘model minority’, and the kinds of expectations associated with this in the context of complaining. The concept of a ‘model minority’ emerged out of a US context to refer to the way in which East Asian migrants came to be idealised as a ‘successful’ minority community by the state. It has since been used by writers in the British context, in reference to South Asian migrants who have historically been seen as ‘well behaved’ and ‘hardworking’ (see Kundnani, 2007). However, this representation of Asian communities in the UK has been altered by decades of the ‘war on terror’, as well as community cohesion agendas, and Muslim communities in particular are now often presented as ‘culturally incompatible’ with British society (Kundnani, 2007). We can see how
expectations around the behaviour of migrant communities might feed into the treatment of all minorities, but particularly Muslim and Asian migrants, in health and social care settings. More specifically, these shared understandings may shape experiences of complaining for those from migrant or minority ethnic backgrounds. Older BAME people in particular may feel reluctant to complain because of perceived expectations of how minority groups ‘should’ behave, but also because of the historical experience of many older migrants who arrived in the UK at a time when racism was much more normalised.
5. Discussion and recommendations

This research demonstrates a clear argument for greater recognition of older BAME people’s experiences of health and social care. Ethnic minorities are more likely to have poorer health, especially in later life, and there is persistently low uptake of health and social care services among the older BAME population. This is due to the large number of barriers that BAME people face, the increased likelihood that BAME people’s needs will not be met and the restrictive assumptions and generalisations regarding service accessibility made by service providers. The matters raised by this research will be of increasing importance in light of the rapidly expanding older BAME population in the UK. We argue that it is therefore crucial that health inequalities, especially in later life when ethnic inequalities are more pronounced, are addressed now in policy and practice.

Moving forward

This research provides insight into how approaches to health and social care in Greater Manchester need to take account of the neglected experiences of its older BAME population.

Greater Manchester Combined Authority (GMCA) does not currently include ethnic inequalities as a priority focus area in the GMCA Population Health Plan 2017-2021 or Primary Care Strategy 2016-2021. This is despite the fact that Greater Manchester is the most diverse region in the UK and its older BAME population is predicted to increase by 159% by 2036.

The GMCA Population Health Plan commits to ‘recognise the importance of relationships and that trust is a valuable commodity’ (GMHSC 2016). However, a key finding of this research reveals a lack of trust in healthcare providers, including local GPs and hospitals, and highlights how levels of satisfaction and confidence in services are lower among the older BAME population in Greater Manchester. The research finds that underlying this dissatisfaction are negative experiences that erode people’s dignity. It is hugely significant that older BAME people in Greater Manchester do not feel as though they are treated with dignity in health and social care settings.

Specifically, the following areas need to be addressed across Greater Manchester to improve older BAME people’s experiences and promote dignity in health and social care:

1. Racism and discrimination.

The research reveals the ways in which older BAME people are directly discriminated against because of their ethnic or cultural background. Discrimination is often, though not exclusively, experienced in public spaces, such as waiting rooms and hospital wards, which compounds the sense of indignity people experience in health and social care settings.

The lack of attention paid to BAME older people’s experiences within policy and practice and persistent ethnic inequalities indicate the extent to which their needs have been neglected. This is despite equality and diversity initiatives across the public sector.
It is vital that these experiences are recognised at senior level within health and social care institutions and taken seriously as part of a widespread problem. In addition, it is important that this knowledge is filtered down and that racism and discrimination are understood as affecting patients’ levels of confidence in health and social care services more generally amongst the older BAME population. A substantial culture shift is therefore required in order for this to happen effectively.

The research finds significant issues in terms of communication and respect for older BAME people’s bodily integrity. It highlights the ways in which key information is withheld from patients, diagnoses and treatment are not adequately explained and intimate bodily practices are performed without full consent or explanation. This reveals the ways in which older BAME people are stereotyped, treated as ‘different’ and dehumanised. Respect for a person’s bodily integrity is a crucial dimension of dignity in everyday health and social care settings.

Moving forward requires not merely a matter of improving language provision or providing culturally sensitive practices, as is often the case in policy targeted at BAME populations, but is rather a question of deep and meaningful change across health and social care institutions to ensure equality of treatment and dignity in care for an already marginalised population. Opportunities to organise training, such as unconscious bias training, should be explored. This would help facilitate closer understanding of the dimensions of racism in health and social care contexts and how that affects older BAME people in particular.

Ethnic and culturalist stereotypes are also at play when local policy and practice works on the assumption that the older BAME population will be sufficiently looked after by family members. This assumption not only plays into crude generalisations about ethnic minorities but also fails to take account of changing family structures. Increasingly, older BAME residents live alone and family members have multiple work and care responsibilities. This needs to be reflected in policy and practice to prevent shortfall in provision, including that of assisted living.

The lack of available data on older BAME people’s experiences is problematic. Data that systematically captures people’s experiences, including of discrimination is needed and GMCA should consider how to integrate this into future processes in order to suitably plan for future needs.

2. Complaints procedures.

A number of barriers persist that prevent older BAME people from challenging unfair or inadequate treatment in health and social care settings. Complaints procedures must be clearly defined and transparent.

Many older BAME people have experienced, or express concern that they may experience, negative consequences for ‘speaking out’ about unfair or inadequate care. It is crucial that this is recognised. It is also vital that stereotypical understandings of how patients from migrant and minority backgrounds ‘should’ behave are redressed to prevent ethnic minorities from being further marginalised.
All patients should be notified of how they can make a complaint within the different health and social care settings in which they are registered and information on how to contact independent regulating bodies and patient advisory groups should be routinely provided.

Channels of complaint need to be clarified and made transparent, and concerns need to be taken seriously to prevent complainants being labelled a ‘problem’. This should be developed in tandem with training that raises awareness of racism and unconscious bias.

3. Individual and community-based approaches to healthcare.

Current policy approaches in Greater Manchester and nationally place a great deal of emphasis on individualised healthcare. This research adds to the important and valid critiques of individualised healthcare approaches, in which individuals are also required to be more ‘active’ and take responsibility for their own health, by highlighting how such an approach is accompanied by a lack of consultation in important decisions. Consequently, such approaches are also counter to responsibilities for enhancing dignity in care, particularly for older BAME people.

Existing approaches, laid out in the Greater Manchester Population Health Plan (GMHSC, 2017) and Primary Care Strategy (GMHSC, 2016), raise the importance of the role of the community in enabling individualised healthcare. Policy approaches need to be reconsidered in light of the findings of this research. It is not feasible to implement a strategy that requires increased self-reliance for one’s health for those who are most marginalised. It is clear that existing services are often inadequately dealing with older BAME people and there is insufficient trust and confidence in services. These issues should take precedent.

Furthermore, a ‘community-centred’ approach does not take account of the huge budget cuts to community organisations and the reductions in local services. Community organisations currently play a vital role in facilitating friendship networks, and providing information as well as formal and informal support, but are struggling to survive in the absence of funding. It is therefore not tenable to place additional responsibilities onto the community and third sector unless this is combined with increases in funding to local groups embedded in communities. This requires a clear commitment to local organisations that are already expert in the needs of their local older population and are BAME-led.
6. References


