Listen Up!

Multiple Myeloma in Black Communities: An Unequal Risk Burden

A Report by The Basil Skyers Myeloma Foundation

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Acknowledgements

This report has been prepared by Dr Sophia Skyers, who is a consultant researcher, and founder and Chair of the Basil Skyers Myeloma Foundation, and Dr Vivienne Kendall, consultant researcher. The process of carrying out this study was supported by an editorial board, which was instrumental in steering the development of the report through to publication, and providing incisive comments at every stage. We cannot thank the members of the editorial board enough. They are as follows:

- Dr Matthew Streetly
  Consultant Haematologist
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  University of Central Lancashire
- Dr Naheed Mir
  Consultant Haematologist
  Lewisham and Greenwich NHS Trust
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  Lewisham and Greenwich NHS Trust
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- Kate Morgan
  Senior Policy Officer
  Myeloma UK
- Dr Ricardo Pinto
  Director of Pinto Consulting

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About the Basil Skyers Myeloma Foundation

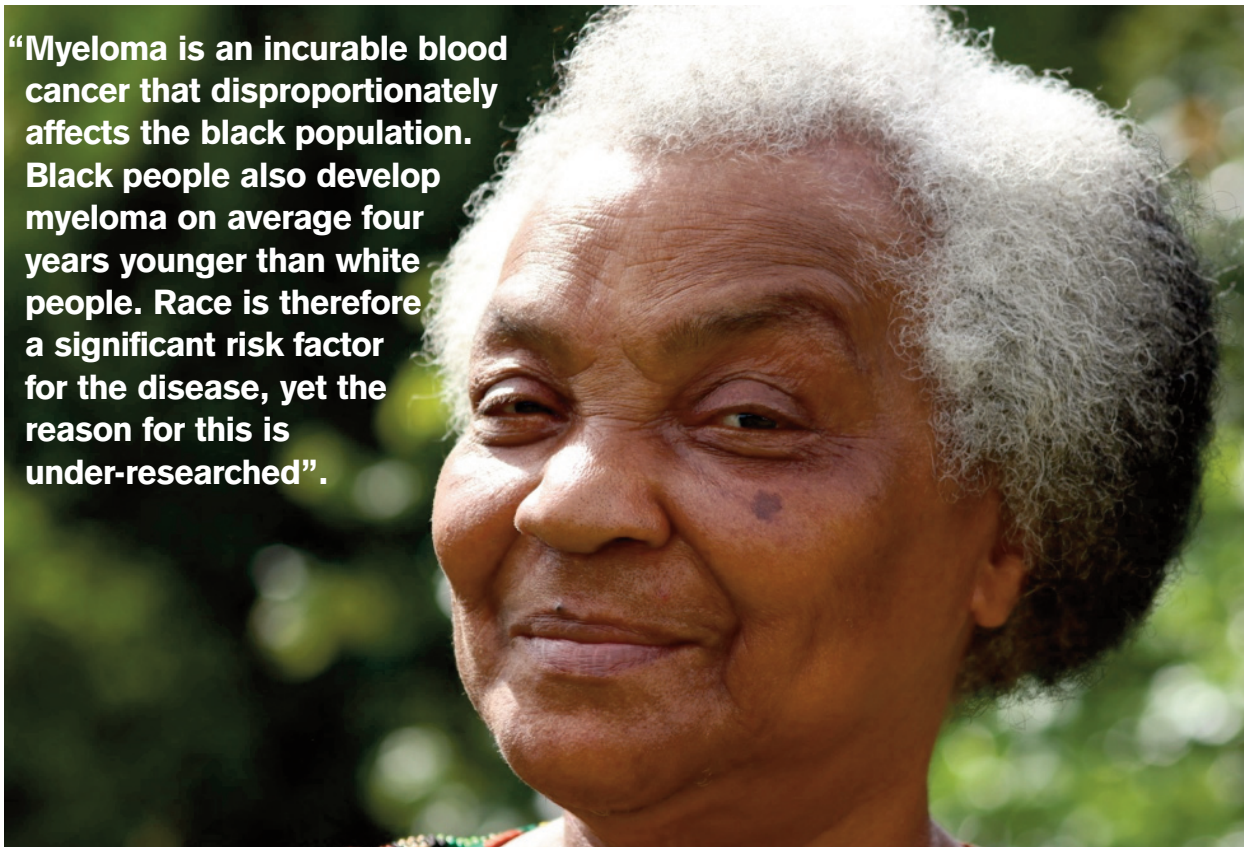
The Basil Skyers Myeloma Foundation was established in October 2010. Its objectives, as set out in its governing document and agreed by the Charity Commission, are as follows:

The relief of sickness and preservation of health for people living with multiple myeloma, their families and carers, in particular but not exclusively:

1. *To provide resources for people living with multiple myeloma and charities that are involved in providing direct services to multiple myeloma sufferers which enhance the quality of their lives and the lives of their families, carers and those who provide support to them.*

2. *To work with public, private and voluntary organisations at a strategic level to raise awareness of multiple myeloma and its impact on sufferers, family members, carers and the wider community.*

3. *To support and fund medical research in multiple myeloma, to the intent that the useful results of such research be disseminated for the public benefit.*



Executive Summary

Multiple myeloma in black populations: Multiple myeloma, also known as myeloma, is an incurable blood cancer that disproportionately affects the black population, and within that, particularly men. Black people develop myeloma on average four years younger than white people and they have a higher rate of mortality, yet this area is under-researched. The NHS has pledged to promote equality in the services it provides, and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population. However, despite very important government advances like the National Cancer Equality Initiative, so far, little effort has gone into focusing attention on the early detection of myeloma in black people, on understanding the reasons for its disproportionate presentation, and monitoring the recruitment of black people to myeloma clinical trials. The current cancer strategy in England focuses on cancers that are preventable through lifestyle, but does acknowledge the special difficulties of rare types of cancer, like myeloma that particularly affect black people. This study is the first to link explicit statements about equality to myeloma, its epidemiology, and to future service provision.

Multiple myeloma will increase with an ageing population: As myeloma is a condition of older people, it is important to recognise that as the UK population ages as a whole, the black population will become even more susceptible to myeloma as its second generation also ages. This should be ringing alarm bells among those who are concerned about services for people with myeloma. Research is critically important and the diagnosis and treatment of myeloma, in general, has benefited immensely in the last ten years from the results of clinical trials and primary research, especially in the area of genomics. The challenge for the future is to monitor coverage of black populations in myeloma clinical trials to ensure that the black population, which has the highest risk burden of the disease, is included. In this, the area of genomics has possibly the biggest potential to provide tools for treatments, tailored to the needs of black communities.

Who should read this report: The report takes a rather different approach from many studies of medical conditions and their implications. As such, it will be of interest not only to medical professionals but also to those concerned with addressing inequalities and with the incorporation of the principles of equality in health. This means local and national government, especially now local government has specific responsibility for health and social welfare, the medical research community, the voluntary and community sector, and the general public.

Recommendations

1 The collection and interpretation of comparative epidemiological data on myeloma and MGUS, including race-disaggregated data, is in need of improvement. More detailed recording of race and ethnicity in Hospital Episode Statistics and also in primary care would enable a more comprehensive understanding of myeloma by race, age, gender and ethnicity.

2 Race and ethnicity should be consistently taken into account in clinical research on myeloma in order to inform the development of clinically and culturally appropriate healthcare services. There is a need to explore the experience of black and minority ethnic groups in myeloma clinical trials, by supporting a continuing dialogue with patient groups, and the voluntary and community sector.

3 Molecular studies should be commissioned to understand the difference in diagnosis, survival and mortality patterns in myeloma between black and white racial groups, and to understand the efficacy of treatments as part of the development of personalised management. It is important also that equality issues are considered within the remit of the cross-departmental Human Genomics Strategy Group set up in response to the House of Lords' 2009 report on genomic medicine.

4 A post-research task group should be established to take forward recommendation 3 above in relation to molecular studies.

5 Wider attention should be given by local authorities, clinical commissioning groups and other public sector partners, within the scope of their responsibilities under the Health and Social Care Act, 2012, and the Equality Act, 2010, to the specific health needs of black and minority ethnic groups. The focus at the local level should also take account of the needs of the black and minority ethnic population, particularly with rare diseases such as myeloma.

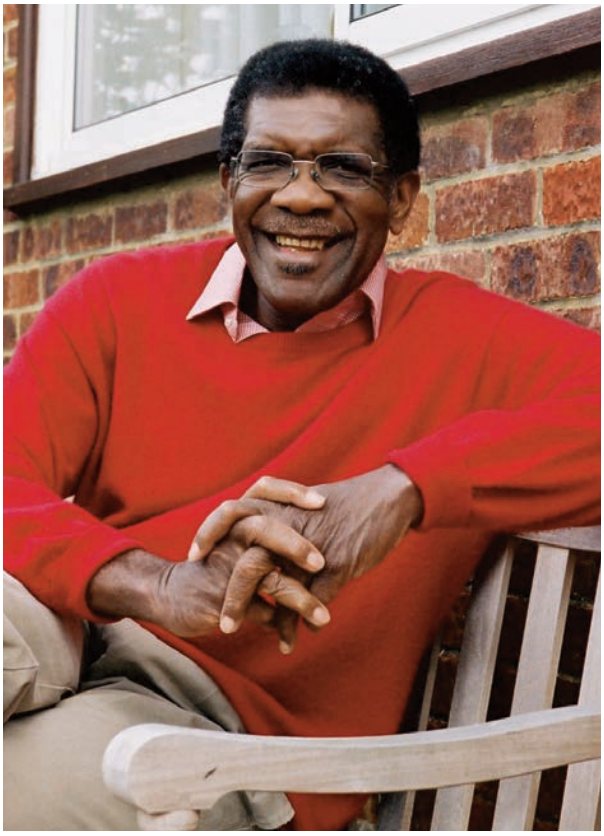
Foreword: Lord Morris of Handsworth

I had the privilege of being one of the founder members of the Basil Skyers Myeloma Foundation, and its first Chair when it was established in 2010. Since that time I have been honoured to act as the Foundation's continuing *'friend'* and *'champion'*.

The research draws attention to a specific area of public health, the blood cancer known as multiple myeloma, where race is directly related to an increased chance of developing the disease. Myeloma is progressive and particularly debilitating, and disproportionately affects two to three times as many people of black African and black Caribbean origin as those from other racial groups. As an important public health issue, it is necessary to understand its presentations across all populations, and as one of the groups most likely to be affected, it is also critically important from a service delivery perspective for the black population, particularly as it increases and as it ages.

The review, which has been led by the Basil Skyers Myeloma Foundation, is the first of its kind in the UK. It represents an initial step in trying to understand the reasons why there is such a disproportionate difference. Myeloma is marked by its heterogeneity, and understanding its presentations in a population that is most affected has the potential to improve outcomes for all patients. If we can begin to understand the factors behind this very important health dynamic, and can begin to identify areas where there are gaps in knowledge, we can then begin to inform the future direction of focused and targeted research, and services.

I was there at the start and now, some five years on, we continue in our work towards achieving our ultimate aim of supporting all patients, families, and carers affected by myeloma; stimulating action within the wider research community, and influencing healthcare agencies to recognise its importance in black communities.



"I was there at the start and now, some five years on, we continue in our work towards achieving our ultimate aim of supporting all patients, families, and carers affected by multiple myeloma".

Preface: Dr Sophia Skyers, Chair of the Foundation

"As you read this report, I want you to keep foremost in your mind that the incidence of myeloma is not a case of abstract statistics. It is about individuals, families, and communities. It is about all of us".

The development and publication of this report has been, first and foremost, a personal journey for me. The late Basil Skyers, from whom the Basil Skyers Myeloma Foundation takes its name, was my younger brother. Basil was diagnosed with myeloma in 2008 and died following a relapse in 2010, at the age of 49.

The Foundation was established in 2010, immediately following Basil's death, to provide practical support and life-affirming resources for people living with myeloma, their families and carers. As well as providing practical support, one of the key aims of the Foundation is pushing forward the frontiers of approaches to the delivery of healthcare services, and influencing clinical research to the benefit of all myeloma patients. This is known as a stratified approach to medicine which divides and subdivides populations into specific groups based on their risk of developing a certain disease, enables earlier diagnosis, and informs the right therapies for patients at the right time. This is a key priority for the NHS, for healthcare professionals, and for the voluntary and community sector working with communities at the neighbourhood level.

As you read this report, I want you to keep foremost in your mind that the incidence of myeloma is not a case of abstract statistics. It is about individuals, families, and communities. It is about all of us. The creation of a Foundation to inspire action, working with and on behalf of myeloma patients, was the last conversation that I had with my brother Basil before he died. As Chair of the Basil Skyers Myeloma Foundation, and as the co-author of this report, I am grateful to everyone for making what was an aspiration that I talked about with my brother, the start of what we hope will be a continuing conversation with policy-makers, healthcare professionals, the voluntary and community sector and the wider research community. The review and its recommendations are for your attention and above all, for your action.

"I very much welcome this report of the Basil Skyers Myeloma Foundation, which is a careful review of an important topic. With over 4,000 new diagnoses each year, this is a cancer that disproportionately affects black African and black Caribbean people.

The report makes an important contribution to our knowledge of the impact of this cancer in black African and black Caribbean people, as well as highlighting areas for action and where further research may be needed. It is not well understood that many cancers affect specific ethnic groups and other minorities differently, and Public Health England has been highlighting the importance of recognising and addressing such inequalities in cancer outcomes as part of its work, including in support of the national Cancer Task Force".

Duncan Selbie
Chief Executive, Public Health England

"Myeloma UK very much welcomes this report, particularly given the importance of the subject area. Whilst there is a higher prevalence of myeloma in the black African and black Caribbean communities, there is very little academic evidence explaining why this is the case or whether their needs and preferences for treatment and care are currently being met by the NHS. This is a major gap in information.

As a minority group, the experience of black myeloma patients needs to be fully understood and met. The report "Listen-up! Multiple Myeloma in Black Communities: An Unequal Risk Burden", is a great first step in highlighting and identifying this knowledge gap and suggesting some ideas and recommendations for where to go next with the discussion.

We applaud the vision of the Basil Skyers Myeloma Foundation in developing and creating this report and hope it will have the desired impact on stakeholders".

Eric Low OBE
Chief Executive, Myeloma UK

"This is an important report highlighting the increased risk of developing myeloma in black communities in the UK. It gives clear recommendations on how best to start understanding why this is the case and how best to support minority ethnic patients who develop this disease".

Dr Matthew Streetly
Consultant Haematologist, Guy's and St Thomas NHS Foundation Trust

1. Introduction

"Black African and black Caribbean people have the highest risk of myeloma of any race or ethnic group in the world. They are twice as likely to be diagnosed with myeloma as the white and Asian population, have twice the mortality rate, and they tend to be diagnosed at a significantly younger age".

1.1 **Multiple myeloma:** Multiple myeloma is the second most common of the blood cancers, yet it is the one that is the least known. It is overwhelmingly the case that the first time people hear the words *multiple myeloma*, is when they, a family member, or a friend have been diagnosed with the disease. Multiple myeloma, or myeloma as it is also known, is a disease characterised by its *heterogeneity* as it takes many forms. It develops as a result of an overproduction of plasma cells in the bone marrow. The cells produce an excess amount of protein in the blood, which can lead to kidney failure. The myeloma cells also crowd out the normal cells in the bone marrow so that red blood cell production is reduced. This results in anaemia, which causes tiredness and shortness of breath. The production of white blood cells is also impaired and gives rise to increased susceptibility to infections, and reduced platelet production can result in bleeding or bruising. Bone pain and thinning or fractures of bones can also occur. Myeloma remains an incurable form of blood cancer, and although patients do respond to treatment and have long remissions, the disease does eventually return, and this is known as a relapse. This is because of the presence of a small population of cancer stem cells that are resistant to the therapies currently used. The number of very powerful drugs that are available for treating myeloma does, however, mean that patients now experience prolonged disease-free intervals, enabling them to enjoy a good quality of life for longer.

1.2 **The risk factors for myeloma:** There are well over 4,000 new diagnoses of myeloma in England each year and the risk of it increases with age.[1] The average age at which patients are diagnosed is 73 years. However, this has begun to change quite dramatically as people in their 30s, 40s, and 50s are increasingly being diagnosed. As more has become known about myeloma, its heterogeneity, and its incidence in the general population, it has also become clear that there is a marked disparity in the incidence of myeloma, and race is a significant risk factor for the disease. While black and minority ethnic people have a lower risk overall from cancer than is the case for the white population, there is a disproportionately higher risk of being diagnosed with certain cancers, and myeloma is one of those.[2] This pronounced disparity is evident at national, regional and sub-regional levels in the UK, and it is important to explore the implications of this for future service delivery. While more is becoming known about myeloma and more effective treatments are available for the general population, there is a continuing void in research about myeloma in black communities, and the efficacy of existing therapies. This is a significant gap, given that black people are the highest risk group in the UK. This research seeks to start the process of filling that void.

1.3 **Aims, objectives, scope, and research questions:** The research examines myeloma from the perspective of the black population in the UK, which has a disproportionate risk of the disease. This report is aimed primarily at policymakers in health and social care, the research community, healthcare professionals, the voluntary and community sector, and the general public. It reviews the existing evidence about myeloma in black communities, so that we can begin to answer questions and begin the process of understanding the factors behind this important health dynamic. The aim of the research is to marshal its outcomes to inform and prompt action within the wider research community, to identify gaps in knowledge, and to influence policy, strategy and research to inform service provision. The study has therefore focused on the following broad research questions.

Research Questions

1. What does the existing evidence tell us about the epidemiology of myeloma in the black population in the UK?
2. What is the current policy context for the delivery of cancer services and why is this important in relation to myeloma in the black population in the UK?
3. What are the implications of changing demographics for myeloma in the black population in the UK?
4. What does the evidence tell us about existing service provision for the black population, specifically in relation to myeloma?
5. What policy initiatives are relevant to future service development?

1.4 The approach to the study is firmly anchored in a social model of health, which recognises that people are both biological and social organisms and that all epidemiology is therefore social as well as clinical. The study embeds the current (albeit limited) epidemiological evidence about myeloma in black communities, within the current policy and legislative landscape for equality in cancer care. In that sense, the epidemiology of myeloma is about more than a description of patterns, trends, and the distribution of the disease. It is also at the heart of the planning and delivery of culturally competent healthcare services, the design and orientation of inclusive clinical research, and the types of service interventions that can be accessed and delivered in a way that is in cultural alignment with all population groups. The research also delivers fundamental support to the concept of stratified medicine,* within the current policy and equality framework. This places people at the centre to ensure the right treatments are given, to the right person, in the right way, and at the right time. These are key healthcare service priorities.

1.5 **Structure of the report:** The report is structured as follows. A short case study is followed by an account of the policy context and legal framework for equality in the delivery of cancer services (Section 2). It also discusses the UK's demographic profile with specific reference to the increasing and ageing black UK population, and the implications for myeloma in that population group. This discussion is important to anchor the research in an understanding about the increasing diversity of communities, and the equality framework that supports the need for policy and practice to be fine-grained and nuanced. A second case study is followed by an examination of the healthcare system in practice, through an analysis of Joint Strategic Needs Assessments (JSNAs) of five local authorities (Section 3). The next section discusses the epidemiological evidence and knowledge gaps about myeloma in black populations (Section 4). The epidemiological evidence is then linked with a discussion of relevant clinical trials and how far they involve, and are therefore representative of black people (Section 5). The report concludes with the key findings from the research and targeted recommendations for policy-makers, healthcare professionals and for the wider research community (Section 6).

1.6 **Methodology:** The study is based on a first general literature search on myeloma in black population groups and subsequent searches of the medical literature for clinical and epidemiological data. The search terms used are listed in Appendix 1. The review did not attempt to conduct a meta-analysis in view of the scarcity of data, but instead set out to examine the current literature systematically and to focus on the most recent evidence wherever possible. Demographic data and social UK and local policy information were obtained from the websites of relevant UK government departments, local authorities and non-governmental organisations. Information on clinical trials and participation in them by people from minority ethnic groups were obtained from literature searches, government documents and other sources.

* Stratified medicine divides and subdivides populations into groups based on their risk of developing a specific disease, and the way they respond to particular therapies.

Case Study One

Basil Skyers (Newark, Nottinghamshire)

Stage III multiple myeloma, Bence Jones Protein: November 2008

"Basil Skyers died at home on 2 August 2010. The Foundation was established in his memory to provide tangible support for all patients with myeloma, their carers and their families, and to influence policy and practice in respect of all myeloma patients".

Basil Skyers was diagnosed with myeloma in November 2008, a month after turning 48. Basil had complained of tiredness to his mother for some time and it was while at the gym with his cousin Howard that Basil noticed that his face was slightly twisted. He went to visit his GP, was told that it was Bell's palsy, was put on medication and recovered from that. After his recovery from Bell's palsy, Basil developed a severe chest infection, and again recovered but this was immediately followed by a severe case of shingles. Basil visited his GP practice a number of times over a three-month period saying that he was very concerned that his chest infection and shingles, and his feeling of being so unwell, pointed to an underlying condition. He was told that was not the case, that he was *'just unlucky'* and that he would get better in time.

Basil became worse and went to another GP in the practice, who immediately did a blood test as one had not been carried out before. That evening, Basil was admitted as an emergency to the Renal Ward at the Nottingham City Hospital. A diagnosis of myeloma was made very quickly at the hospital. Basil was given an MRI scan to assess the extent of bone damage, and lesions were found on his spine and on his rib cage where the myeloma had attacked the bone. Basil's paraprotein levels were also very high and he was given a course of thalidomide and dexamethasone, and this knocked the myeloma back until it was undetectable.

Basil went back to work whilst still undergoing chemotherapy, and then went on a family holiday for two weeks. In April 2009, he underwent an autologous stem cell transplant and the myeloma remained undetectable. After just seven months however, Basil relapsed and was then put on a course of Velcade, to which he initially responded, but then relapsed while on the treatment. He was admitted to hospital and prescribed Revlimid, but that proved ineffective and the myeloma progressed rapidly.

2. The policy and demographic context

"Cancer diagnosis and treatment have featured prominently in the UK's healthcare changes of the last ten years; and so have measures on ensuring equality of care. However, little attention has been given to the needs of specific black and minority ethnic populations, which have significantly greater susceptibility to specific cancers like myeloma".

2.1 **The equality framework for the delivery of healthcare:** The policy and regulatory framework for equality, and population demographics are the essential background to understanding the epidemiology of myeloma in black populations, and what is currently being done, or not being done by local and national policy makers to tackle race-specific issues. The principle of *equality* is at the centre of legislation, specifically the Equality Act 2010, and individual initiatives designed to ensure high standards in health and social care and service improvements. This provides an important framework for a discussion about myeloma in black populations.

2.2 The *NHS Constitution*[3] states that the NHS should provide a comprehensive service that is available to all groups, according to its statutory duty to promote equality. This includes a focus on areas where health outcomes in certain groups are failing to keep pace with those of the general population. The *National Cancer Equality Initiative*[4] has identified a number of policy drivers for addressing inequalities in cancer, and the *NHS Outcomes Framework*[5] embraces addressing health inequalities as central to improving performance in the health and care system. The Department of Health's *Improving Outcomes: A Strategy for Cancer* recognises that developing the equality evidence base is central.[6] This study contributes to the limited evidence about myeloma in black populations by marrying what is currently known to the changing demographics in which an increasing and an ageing black population is most at risk of the disease.

The NHS *Operating Framework for 2015/16* is intended to be a tool, which reflects the landscape of the health and care system so that it can be better suited to approach the many challenges that the system faces.[7] In relation to myeloma, as is the case for other cancers, this requires good quality evidence about its incidence in an increasingly diverse population.

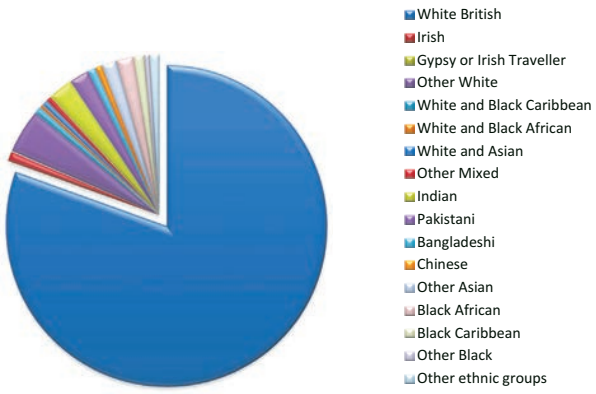
2.3 The *Equality Delivery System* also provides a voluntary framework for all NHS organisations to performance manage health and social care organisations against their legal commitments.[8] The *Joint Strategic Needs Assessment* (JSNA) is also relevant to this discussion as a key statutory process through which local authorities, clinical commissioning groups and other public sector partners, now responsible for local care provision, are required jointly to describe and plan for the current and future health and wellbeing needs of the local population they serve. This again is reliant on a credible evidence base to inform priorities, taking full account of population diversity. The National Institute for Health and Care Excellence (NICE) has set itself equality objectives and its public health guidance is associated with underlying socioeconomic factors and with inequalities in access for certain disadvantaged groups to healthcare and opportunities to improve their health.[†] However, the NICE *Guidance on the diagnosis and management of myeloma*, which is currently out for consultation and is due to be published in 2016, recognises the disproportionate impact of myeloma in black populations, but has not, at the time of writing, identified any sub-group as needing specific consideration.[9]

[†] NICE provides national guidance on quality standards on the promotion of good health, the prevention and treatment of ill health, and social care; advice on medicines and prescribing; and indicators for the Quality and Outcomes Framework for GP services and the Clinical Commissioning Group Outcomes Indicator Set (CCGOIS).

2.4 This research therefore seeks to link policy statements about equality, to the epidemiology of myeloma and to changing demographics. At the same time, it seeks to contribute to the limited evidence base about the population that has the highest risk of myeloma, and to initiate a discussion about it as it is not currently on the agenda.

2.5 **The demographic context and myeloma in the UK:** The current population of the UK is 64.1 million and in England it is 53.9 million.[10] The population structure across England and in other UK countries has been transformed during the last fifty years. As is the case for most of Western Europe, the UK has become more racially and ethnically diverse as a result of inward migration. The white British group accounts for more than 80% of the population and the black group is the second largest minority ethnic group in England and the UK, after the Asian group (Figure 1).

Figure 1: Demographic profile for England and Wales, 2011



Source: ONS Nomis KS201EW Ethnic group England and Wales 2011[11]

2.6 In the UK, by far the greatest proportion of black people live in England, and London is home to more than half the UK's black and minority ethnic population. The West Midlands has the next highest proportion, followed by, the East, the East Midlands, and Yorkshire and Humber. In 2011, 58% of the black African population, 58% of the black Caribbean population, and 61% of other black British people lived in London.[12] Within the English regions, the black population is mainly resident in the major urban centres, particularly Manchester, Birmingham, Leeds, Sheffield, Leicester, Nottingham, and Northampton. The relative numbers of the black and minority ethnic population in England are illustrated in Figure 2.

The policy framework – Key Points

1. The Health and Social Care Act, 2012 and the Equality Act, 2010 require public bodies and the NHS to reduce inequalities.

2. The Department of Health's 2010 Strategy for Cancer focused mainly on prevention, diagnosis and treatment of the cancers that affect the largest number of people, and which are preventable by appropriate lifestyle changes, for example diet, smoking, alcohol, and exercise.[6]

3. As part of the National Cancer Strategy, the National Cancer Equality Initiative found ethnic variations in cancer incidence, lower cancer awareness in minority ethnic groups and a need for culturally relevant information about cancer symptoms.[4]

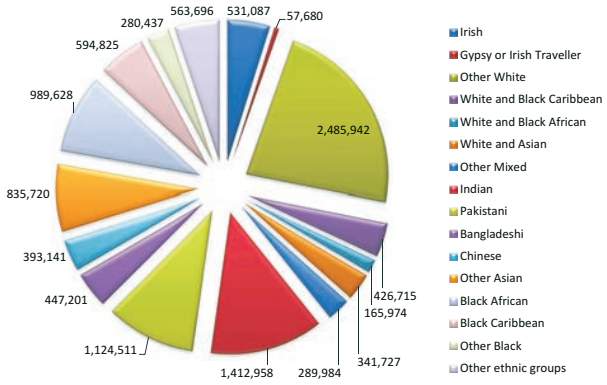
4. The Department of Health's Race Equality Scheme found that minority ethnic groups experience poorer health than others and also poorer access to services.[13] The DoH Quality and Outcomes Framework was stated by the King's Fund in 2010 to have not improved health outcomes, or reduced health inequalities. This does not tackle detailed issues related to rare diseases, such as myeloma, which make up 54% of all UK cancer deaths.[14]

5. NICE Guidance on the diagnosis and management of myeloma, due in January 2016, recognises the higher susceptibility to myeloma of people of African and African Caribbean origin, but specifically states that no patient subgroups have been identified as needing specific consideration.[9]

6. The National Cancer Patient Experience Survey found a need for more effective communication between GPs and minority ethnic patients, and better GP diagnostic skills; examination of the quality of care received by these patients, the number of GP consultations before referral, and the proportion of cancer patients who present as an emergency.[4]

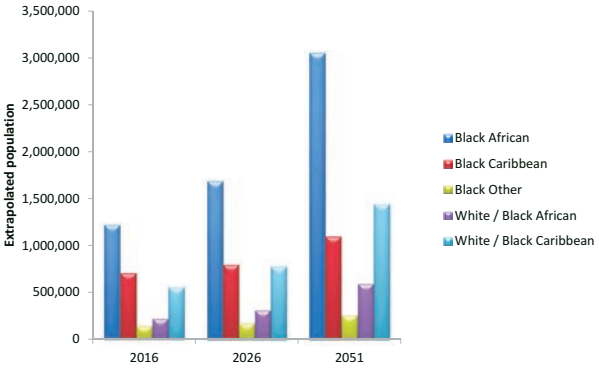
7. A 2014 survey by BME Cancer Voice, housed and serviced by the Black Health Initiative (BHI), also found a poorer overall patient experience among black and minority ethnic groups.[15]

Figure 2: Population of England and Wales 2011: All ethnic groups except white British



Source: ONS Nomis KS201EW Ethnic group England and Wales 2011[11]

Figure 3: Population of black minority and mixed white and black groups projected to 2051, England and Wales



Source: Lievesley 2012[12]

2.7 **The implications for multiple myeloma of an increasing and ageing black population:** There has been a significant recent increase in the proportion in the general population of people aged 40-54, and 65+. By 2026, after the white Irish group, the group with the second highest proportion of people aged 65+ will be the black Caribbean group. This group will make up 13.4% of the whole population, and one third of the population aged over 50.[12] As well as an ageing population, the current projections suggest that both the numbers and the proportions of people from black and minority ethnic groups will increase in the UK, and that they will represent a larger proportion of older people. In England and Wales it is estimated that by 2026, there will be over 1.3 million people from black and minority ethnic groups aged 65+. By mid-century, the black African and black Caribbean groups are estimated to reach a combined population of more than 4 million. The total black population including those of dual heritage, that is, the mixed white and black African and mixed white and black Caribbean group, will reach more than six million people in England and Wales. The dual heritage population is the fastest growing group in percentage terms in the UK.[15]

2.8 There are important implications for myeloma, in that its incidence will be compounded in the black population as it ages, because age and race are among the key risk factors for the disease. Second generation black people fall into the increasing 40-54 age group and are also part of the projected increase in the 65+ black population.‡ The first generation black population predominantly fall into the 70-80+ category. This underlines the need for inclusive clinical services and clinical trials that are culturally competent to test the efficacy of medicines and to inform service development.

2.9 **Cultural competence in healthcare:** The 2010 and 2013 reports of the national cancer patient experience survey revealed concerns from black and minority ethnic patients over poor communication and a poorer patient experience. Further analysis of the 2014 survey identified differences between the perceptions of care held by patients who initially entered treatment through an emergency department route, and those who began treatment following a planned pathway referral. Patients who entered treatment through an emergency route were less likely to give positive scores than others. As patients who present as an emergency are likely to have a poorer outcome than those who have received earlier care from a GP, this reinforces the need for diagnosis as early as possible in the course of illness. This is particularly important for patients with rare cancers, who have reported poorer care.

‡ First generation people are those who migrated to the UK, and second generation people are those who are either born in the UK, or grew up in the UK from childhood.

2.10 Similarly, BME Cancer Voice, which is housed and supported by the Black Health Initiative (BHI), revealed a number of issues relating to communication between healthcare professionals, lack of suitable prosthetics, and a poorer overall experience among black and minority ethnic cancer patients.[15] A critical barrier is communication across cultural boundaries. With the proportion of people from minority ethnic groups steadily increasing, it is important to attend to this aspect of care. While medical students and nurses are now trained to take cultural and religious needs into account, there is also a need for cultural awareness to be part of continuing medical education. At the onset and throughout the course of a major medical condition such as myeloma, the issues associated with cultural sensitivity are important and effective communication is critical.

Demographics – Key points

1. The black group is the second largest minority ethnic group in England and the UK, after the Asian group, and is mainly resident in London and the UK's other main metropolitan centres.
2. In England and Wales it is estimated that by 2026, there will be more than 1.3 million people from black and minority ethnic groups aged 65+.
3. The proportion of black people in the older age group is increasing and this has major implications for the incidence of myeloma, as it predominantly affects older people.
4. Cultural competence is an important consideration in providing healthcare services to black and minority ethnic groups, including clinical trials.

"By mid century, the total black population including those of dual heritage, that is the mixed white and black African and the mixed white and black Caribbean group, will reach more than six million people".

3. The health system and the needs of black and minority ethnic groups in practice

"Out of five local authorities examined (Lambeth, Lewisham, Birmingham, Nottingham and Stockton-on-Tees), Birmingham is the only one that has identified, in its Joint Strategic Needs Assessment, the gaps in knowledge and research on cancers in black and minority ethnic groups".

3.1 **Joint Strategic Needs Assessments:** The Joint Strategic Needs Assessment (JSNA) analyse the health needs of populations to inform and guide the commissioning of health, wellbeing and social care services within local authority districts. The main aim of JSNAs is to accurately assess the health needs of local populations, and to develop health and well-being strategies and commissioning plans to improve the health of individuals and communities. Local Authorities (LAs), clinical commissioning groups and other public sector partners are required by the Health and Social Care Act, 2012 to describe jointly, in JSNAs, the current and future health and wellbeing needs of the local population they serve. The agencies are also required to jointly identify and agree priorities for action to address the determinants that affect health and wellbeing in the area. This review has examined the population demographics and cancer outcomes in a number of examples of LAs with varying proportions of black African, black Caribbean and other black residents, and varying levels of affluence and deprivation.

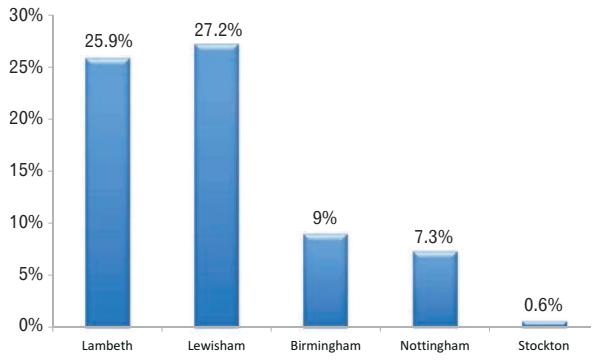
3.2 The local authority areas selected, which represent a range of smaller and larger black and minority ethnic populations, are:

- London Borough of Lambeth (London Region)
- London Borough of Lewisham (London Region)
- Birmingham City (West Midlands Region)
- Nottingham City (East Midlands Region)
- Stockton-on-Tees (North East Region)

3.3 The Health and Social Care Act 2012 introduced duties and powers for Health and Wellbeing Boards (HWBs) in relation to JSNAs.[16] The main duty of HWBs is to encourage integrated working between the NHS, public health and social care providers and to deliver services based on the best evidence of local need.[16]

3.4 **What the JSNAs can tell us – local demographics:** The key demographics and health indicator data for the five local authorities are summarised in Figures 4-8 and are set out in full in Appendix 2. A comparison of these local authority districts reveals many common factors and many questions, which are being addressed in JSNAs. In the context of this research however, there are unanswered questions relating to the needs of specific population groups, particularly black Africans and black Caribbeans. The five local authorities have a population of similar size (2 – 300,000), except Birmingham City which, like London, has a much larger population (~1.1 million).[17-21]

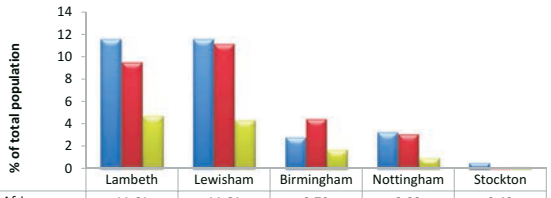
Figure 4: Black groups as a proportion of the total population



Source: Office for National Statistics[22]

3.5 The two London boroughs have a much higher proportion of black residents than the other local authority districts, and Lewisham has the largest African and African Caribbean population. Birmingham and Nottingham also have high proportions. Later analysis also considers the proportion of mixed black and white groups, but these are represented in much lower numbers.

Figure 5: Composition of black ethnic groups in each local authority



	Lambeth	Lewisham	Birmingham	Nottingham	Stockton
Black African	11.61	11.61	2.79	3.23	0.49
Black Caribbean	9.53	11.18	4.44	3.07	0.04
Other black British	4.77	4.37	1.75	0.96	0.06

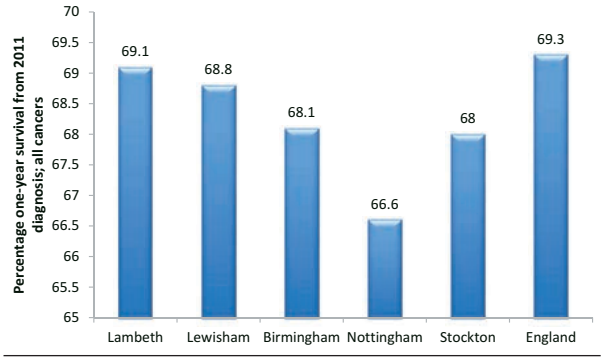
Source: Office for National Statistics[21]

3.6 Black African and black Caribbean groups are in approximately equal numbers in the two London boroughs, with slightly more people of African origin. However black Caribbean people outnumber black Africans in Birmingham. In all five local authority districts, black African and black Caribbean people greatly outnumber those in the Other Black group. The relative proportion of minority ethnic groups is predicted to rise in the coming years, but this increase was not referred to in any of the JSNAs examined in this review.

3.7 **What the JSNAs can tell us – local health:** The first main finding is that the main long-term conditions that contribute to illness and mortality are the same for all, that is circulatory problems, especially coronary heart disease; respiratory problems and asthma, and cancer, particularly lung, colon and prostate cancer.[23-27] The JSNAs also show that there is little difference between the five LAs in terms of life expectancy.[28,29] It must be borne in mind however, that the life expectancy data presented, represent the population average. The average masks differences in terms of race and socioeconomics, where minority ethnic groups and those from lower socioeconomic levels have lower life expectancy than those with higher levels of affluence. The predicted life expectancy for women is consistently higher than that for men. The five LAs all show levels of deprivation, and life expectancy within them is lower than the average for England as a whole.

3.8 Looking more closely at the data for cancer, differences start to emerge. For all cancers, including myeloma, the percentage of patients surviving one-year from diagnosis in 2012 is an effective indicator of early diagnosis and effective treatment. The data show that the one-year survival rate in four local authorities is similar, but Nottingham has a rather poorer outcome (Figure 6).[30] These data cover a wide field of cancers, some of which are fully treatable, and some of which, like myeloma, are incurable, and therefore many factors are involved in the data. This is another example of where it would be very informative to have access to disaggregated data, since these data are not able to indicate the race of patients, or their age.

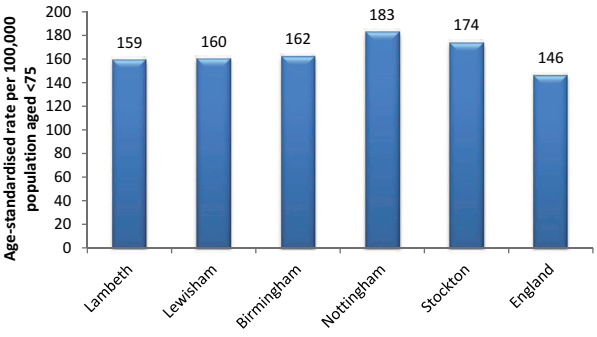
Figure 6: Percentage one-year survival after 2011 diagnosis, all cancers



Source: Health and Social Care Information Centre[30]

3.9 The data for premature deaths from cancer (Figure 7) show that all five LAs have significantly higher early death rates than the average for England, and the levels for Nottingham and Stockton-on-Tees are notably higher than the two London authorities and Birmingham.

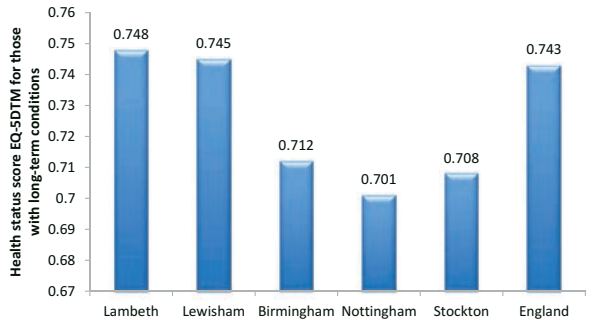
Figure 7: Premature deaths (<75 yrs) from cancer 2010 – 2012



Source: Lambeth & Southwark's Public Health Intelligence Team and Local Authority Health Profiles 2014[17-21]

3.10 The last general health indicator that can provide useful comparison between local authorities is the NHS Outcomes Framework data for the health-related quality of life for people with long-term conditions (Figure 8).[6] While this includes people with conditions like diabetes and heart disease as well as cancer, it is measured by means of a standard questionnaire given to all patients, and therefore does give an indication of the level of their contentment with the general healthcare they receive.

Figure 8: Health-related quality of life for people with long-term conditions*



Source: NHS Outcomes Framework – GP Patient Survey[6]

* Directly standardised average health status score (EQ-5DTM) for individuals aged 18 and over who identify themselves as having a long-term condition

3.11 It can be seen that patients with long-term conditions in the two London LAs are more content than the England average, and the worse perceived health of people is in Birmingham, Stockton-on-Tees, and particularly in Nottingham. Patients in Lambeth and Lewisham indicate a better standard of contentment than the average for England.[6] These data are derived from the annual GP Patient Survey; a standardised questionnaire, which makes no reference to cultural sensitivity in its content. It is also the case that many population groups are reticent about information gathering of a personal nature, expectations of services may differ among populations in different areas, and the response rate to the survey was only 34%.[6]

3.12 **JSNA-based policies to address local health need:** It is noticeable that in the JSNA policies, the LAs set out their agendas in the field of cancer as relating to those which are known to have a relationship to modifiable factors such as use of tobacco, alcohol, obesity and hypertension. There are no data available for the outcome of myeloma in individual local authorities, still less by race. Out of the five LAs, Birmingham, the second most racially and ethnically diverse city in the UK, apart from London, is the only one that has identified the issue of cancer in relation to minority ethnic groups. The Birmingham JSNA has identified the following gaps in knowledge:[25]

- There is little specific research available on the health needs of older minority ethnic groups, and health needs may also differ across generations.
- More research on cancers by ethnic group is required.
- More local work is needed on social determinants in relation to the health of older people, for example, recording of social care information in terms of the cause and effects of social isolation.
- Further work is needed on modelling the prevalence of long-term conditions, taking into account the population differences between Birmingham and the England average.

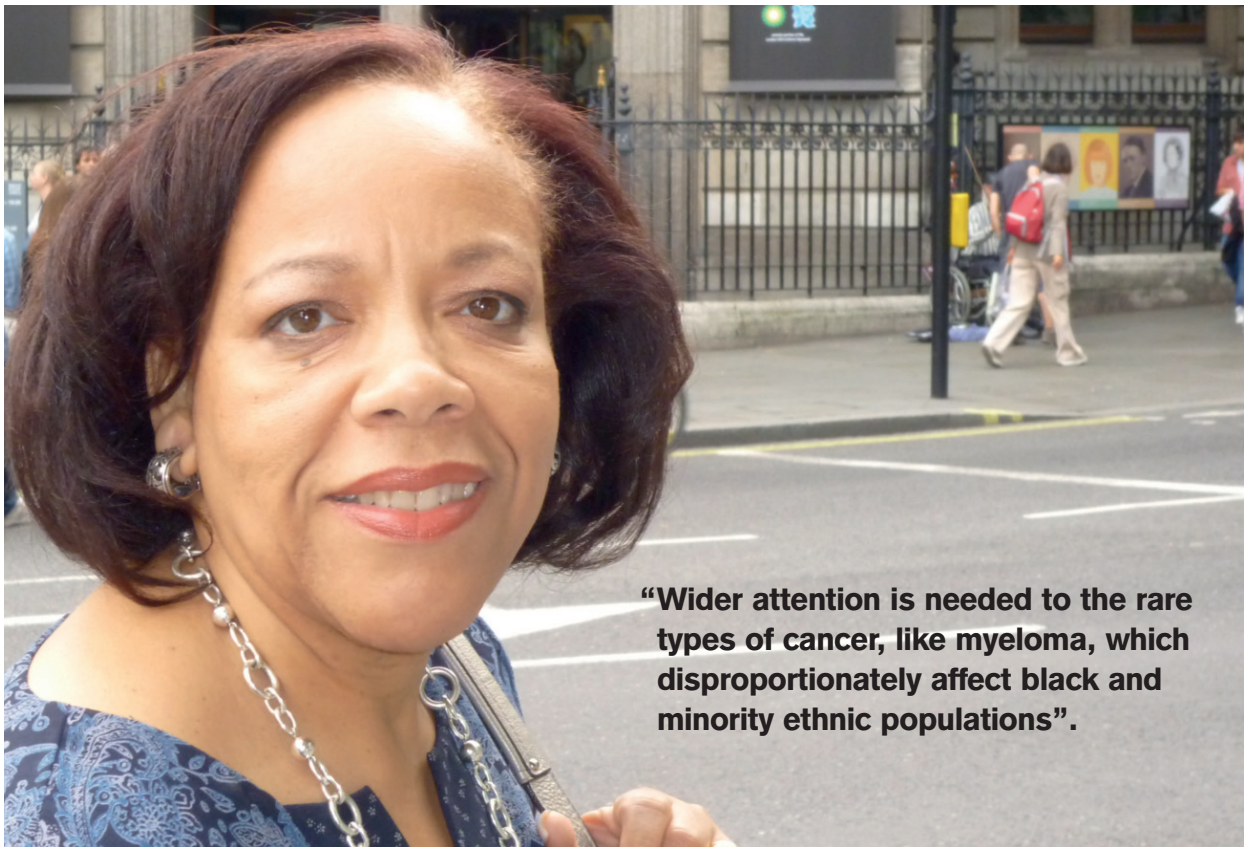
3.13 The London Borough of Lambeth's Health and Well-Being Strategy, developed from its 2008 JSNA, notes that avoidable health inequalities exist between different ethnicities and that action can be taken to reduce or to eliminate them.[31] The Borough's health priorities are mental health, hypertension, diabetes and heart disease, and for the over 65s, early detection, management and improving quality of life for those with long term conditions, and also targeting smoking, alcohol use and obesity.

3.14 In its Local Health Plan for 2013-18, the London Borough of Lewisham has taken into account the rising numbers of people with long-term conditions with the ageing of the population, many of whom will have more than two conditions.[32] The population of Lewisham, which is home to the largest black Caribbean and black African population in the UK, is expected to become increasingly ethnically diverse as the current population ages, and this demographic change does need to be factored into future service plans. The Lewisham JSNA notes that some groups are at greater risk of certain diseases commonly treated in primary care, for example, diabetes is more common in black and Asian populations. It also acknowledges that long-term conditions also increase with age and are more prevalent

among deprived communities. It calls for earlier identification, improved integration and quality of care to delay or reduce the impact of disease and reduce emergency admissions, which are indicative of lower awareness of cancer symptoms in patients, late presentation or poorer primary care, and have a poor outcome.[32]

3.15 Nottingham has the highest proportion of people of mixed black and white, and other mixed ethnic groups outside London. The health priorities identified by its Health and Wellbeing Strategy 2013-16 are reducing alcohol misuse to reduce the number of citizens who develop alcohol-related diseases, to integrate health and social care services to ensure better care is offered to older people and those with long-term conditions, and to improve mental health.[33] The Strategy does mention cancer as an example of a long-term condition, but not in the context of existing gaps in knowledge about prevalence and the experiences of black and minority ethnic groups.

3.16 The Joint Health and Wellbeing Strategy for 2012-18 for Stockton-on-Tees sets the target of developing programmes to find and treat people who are at risk of cardiovascular disease, cancer, respiratory disease and diabetes.[34] It again emphasises the high levels of heart disease, cancer and respiratory illness, high prevalence of smoking, excessive alcohol use, obesity and lack of exercise leading to preventable disease, and health inequalities. Early death from cancer in Stockton-on-Tees is significantly higher than the England average, and cancer is the second largest contributor to premature death after cardiovascular disease. Hospital admissions for the black community in Stockton-on-Tees show the highest level of emergency admissions of any ethnic group (46.6% of black admissions, compared with 45% for the England average for black people, and 39.5% for white people in Stockton).[34] This suggests that even with relatively low numbers of black people in this LA, their health outcomes do not match those of other population groups, and need to be examined further.



3.17 Analysis of the health outcomes in the five LAs has shown a focus on detection and treatment of coronary heart disease; respiratory problems, particularly chronic obstructive pulmonary disease and asthma, and cancer, that is, the preventable long-term conditions, which affect the largest numbers of people, in line with overall national cancer strategy. The findings from the JSNAs and the strategies for health and well-being that followed them show some awareness of the increased susceptibility of minority ethnic groups to particular conditions. As already stated however, only one authority, Birmingham City, is specifically aware of the greater susceptibility of some black and minority ethnic groups to particular cancers and has highlighted the importance of targeted action to fill gaps in knowledge. Wider attention is needed to the rare types of cancer, like myeloma, which disproportionately affect black and minority ethnic populations. Detailed race and ethnicity of residents receiving healthcare in primary care or hospitals is still not fully recorded and this hampers analysis. Moreover, greater cultural awareness and sensitivity from healthcare providers could enable more effective communication, and therefore the earlier detection and treatment of myeloma.

Findings from five local authorities – Key points

- While all five local authorities examined in this report (the London Boroughs of Lambeth and Lewisham; Birmingham City; Nottingham City, and Stockton on Tees) showed a level of deprivation, there was no direct correlation between communities with a high level of deprivation and a high proportion of minority ethnic groups.
- The main medical conditions affecting the five authorities were circulatory problems, especially coronary heart disease; respiratory problems, particularly chronic obstructive pulmonary disease and asthma, and cancer, particularly lung, colon and prostate cancer.
- JSNAs appear to be focusing on the largest health problems rather than attempting to reduce inequalities in specific black and minority populations. This has implications for rare cancers like myeloma, which disproportionately impact black populations.
- The detailed race and ethnicity of residents receiving healthcare in primary care or hospitals is still not fully recorded and this hampers analysis, including for cancers like myeloma, which has a higher incidence in the black population.
- Only one out of five authorities, Birmingham, mentions the need for more analysis of cancer in relation to minority ethnic groups.
- Wider attention is needed on the importance of early detection of specific cancers, like myeloma, which reflects on the need to improve the awareness of healthcare professionals in noticing, reporting, diagnosing and treating symptoms.
- Wider attention is needed to providing culturally appropriate information and care, suitable to the individual; something that is rarely considered as a strategic need.

"The detailed race and ethnicity of residents receiving healthcare in primary care or hospitals is still not fully recorded and this hampers analysis, including for cancers like myeloma, which has a higher incidence in the black population".

Case Study Two

Pauline Johnson (London)

Stage IIIA IgG kappa multiple myeloma – July 2009

"I was diagnosed in 2009, aged 46, after having a series of illnesses and infections since at least 2007. I was eventually admitted to hospital with a gall bladder infection, and ended up having it removed. After that, the doctors told me that I had a very low blood count and I was given a blood transfusion".

Before being discharged, I was told to go to my GP after six weeks and to ask for a blood test to check that my blood levels were back to normal. I had the blood test but my blood counts failed to come back up, so my GP said he would do a thyroid test. I mentioned to my GP that my hair was very dry and brittle, rather like straw, and that it was falling out. I was also losing weight but that suited me fine, as I didn't attribute my weight loss to anything negative. In my vanity, it was my hair that I was most concerned about. The thyroid test came back negative and my GP told me he was unhappy and that he wanted to get to the bottom of why the blood counts were so low.

My GP referred me to a consultant haemato-oncologist at St George's Hospital and I was given a bone marrow biopsy. The hospital called me back a week later and as I sat in the reception, there were whispers between the nurse and the reception staff, and lots of comings and goings. I was then called in to see the consultant and a nurse was there. That was when I was told that I had multiple myeloma but hearing it, it didn't ring true because I didn't know what he was talking about. I had never heard of multiple myeloma. I had a notepad and pen and kept asking questions, and in hindsight, I think they were rather surprised that I was not more upset. The consultant said that he wanted to start me on chemotherapy the next day and that was when it hit me. It never dawned on me that I had cancer. I never, ever thought it was cancer. It never ever crossed my mind that it would be that.

The first stage following my diagnosis was a series of CT Scans and X-rays to ensure that the myeloma had not eaten into my bones, and I was called back to the hospital quite a bit. My paraprotein level was 49, which is very high, but apart from my hair falling out, and some bruising that I put down to banging myself, I had no symptoms. The doctors told me that they could not understand how I was still standing. I was started on seven courses of chemotherapy in July 2009 comprising thalidomide, dexamethasone and cyclophosphamide for six months, and had to have extended treatment because of recurring infections. I was in partial remission by December 2009, and was then given an autologous stem cell transplant in April 2010, which meant being in isolation for four weeks.

When I was diagnosed my initial prognosis was six months, because of the severity of the myeloma and the extraordinarily high levels of paraprotein in my body. I am now five years post-transplant, which is a huge success, any way you choose to measure it. I lead a very active and a very full life. I have learned to play the cello and I have reached Grade 2. This is coupled with all the joys of bringing up my daughter, who has gone to university this year. I have been a Trustee of the Basil Skyers Myeloma Foundation since it started and want to do more community outreach so that myeloma is more understood in the black community.

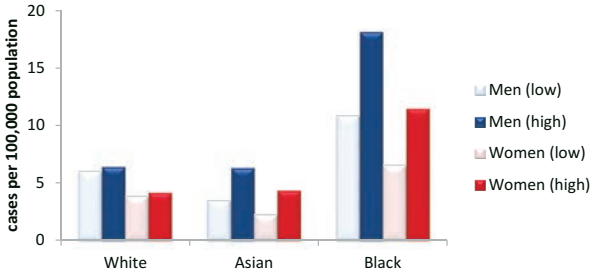
4. The epidemiological evidence

"Black African and black Caribbean people have a higher incidence than white people of myeloma. They develop myeloma earlier and have a higher mortality rate. Black men have a higher disease burden than black women".

4.1 **The importance of understanding race and ethnicity:** The terms *race* and *ethnicity* are often used interchangeably in policy, scientific and medical literature in relation to black and minority ethnic groups. This is inaccurate. For clarity, *race* refers to a person's physical characteristics (phenotype) as defined by their genetic identity (genome), while *ethnicity* refers to cultural features, including nationality, regional culture, ancestry, traditions and language. It is important to understand this distinction, as myeloma is more prevalent in black people as a racial group, while ethnicity is important in understanding access to services from the perspective of culture.

4.2 **The incidence of multiple myeloma by race:** Myeloma is the 17th most common cancer in the UK, accounting for 1% of all new cancer diagnoses.[35] The incidence of myeloma has increased overall in the UK since the mid-1970s; in 2012, there were 4,190 new diagnoses of myeloma. At an international level, there is significant variation between countries in that the highest incidence is in Australia and New Zealand, and the lowest is surprisingly in Western Africa. The reasons for these differences are not known but may reflect the prevalence of risk factors, the use of screening, variations in diagnostic methods, and access to diagnostics.[36] In the UK, while black and minority ethnic groups are at a lower risk from cancer overall than the white population, they do have a disproportionately higher risk of being diagnosed with some specific cancers, of which myeloma is one.[2] Black people have the highest risk of myeloma of any race or ethnic group in the world. Race is therefore a significant risk factor for the disease, and black people in the UK are 2-3 times more likely to be diagnosed with myeloma than white people.

Figure 9: Ranges of incidence of multiple myeloma in three UK ethnic groups

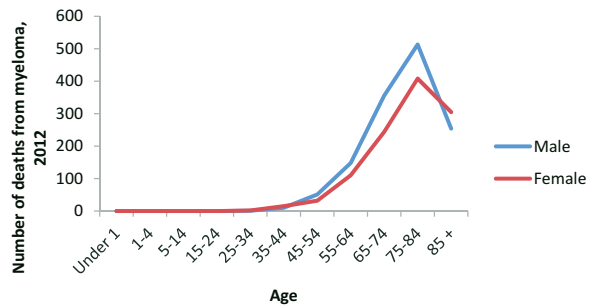


Source: National Cancer Intelligence Network/Cancer Research UK[2]

4.3 Figure 9 shows the age-standardised incidence rates for men and women with myeloma, by race per 100,000 of the population. The rates for the white and Asian populations are broadly similar while the rates for black men and black women are significantly higher. This distribution has been evident in the UK for some 40 years. The ranges, low to high, are due to the methodology used to account for missing or unknown data: out of a total of 17,357 cases identified, 18% had no known ethnicity.[2]

4.4 **Mortality and survival rates:** In 2013, registered deaths from myeloma in England and Wales totalled 1,333 males and 1,116 females.[37] Very few deaths occurred before the age of 30, rising to peak mortality at around 80 years of age. There are currently no disaggregated data for myeloma by race, and this is therefore an important gap in the evidence that needs to be filled, given that myeloma is strongly delineated by race.

Figure 10: Mortality from multiple myeloma



Source: Office for National Statistics[37]

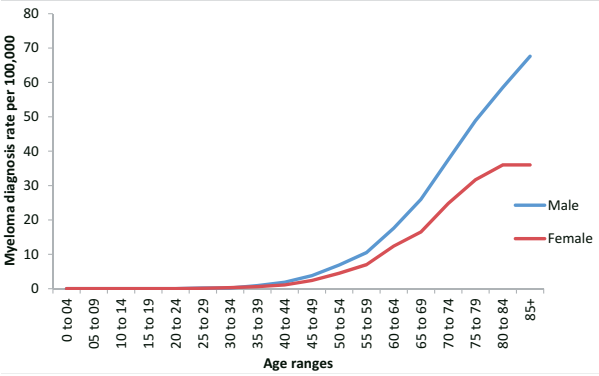
4.5 There are limited studies exploring survival rates by race. A number of studies based on the US Surveillance Epidemiology and End Results (SEER) database of almost 40,000 myeloma patients have consistently suggested twice the mortality rate in black populations as a result of myeloma compared with white populations.[38] A more intensive and extensive investigation of the large-scale SEER dataset has, however, shown a different picture.[39] In all patients, black and white, under 50 years of age, there was no difference in survival, but above that age, 5-year survival was found to be significantly greater among black people than among white people. The SEER study also found that while disease-specific survival was greater for black people than for white people, over time, improvements in survival were far more pronounced in white people than in black people. This could be due to more limited access to healthcare among black people in the US, and limited access to newer therapies, as healthcare is not free at the point of delivery.

4.6 In the UK, the results of a study by the National Cancer Intelligence Network (NCIN) mirror the survival advantage seen in the US study of the SEER database. The NCIN study estimated the incidence and survival rates for patients with myeloma by ethnicity by using the National Cancer Data Repository (NDR) to identify registrations of myeloma in English cancer registries from 2002 to 2007. Ethnicity was categorised using records in linked Hospital Episode Statistics. The study found that the incidence of myeloma was highest in the black population, but that relative survival at 1, 3 and 5 years was higher in the black group compared with the white group. The risk of death was also found to be lower in the black group than in the white group.[40] However, recording of data does not capture everything. Registration is poor, and ethnicity and race are often confused. Data recording is significantly better than it was, but still patchy and there is room for major improvement.

4.7 A number of important issues are therefore raised in relation to myeloma in black populations. As the disease is characterised by its heterogeneity, if survival is longer among black people, this could indicate that a different or less active subtype of myeloma may be more common in black people than in white people. The evidence points to the need for molecular studies to understand the reasons behind the difference. This is in alignment with the concept of stratified medicine and the shift towards more targeted myeloma therapies, as it has the potential to further the development of personalised management and treatment. It should also be noted that length of survival does not say anything about health outcomes in relation to quality of life and patient experience. This needs to be explored further.

4.8 **Age of diagnosis:** The risk of developing myeloma increases with age. According to 2014 data, the average age at which patients are diagnosed in the UK is 73 years.[41] Myeloma does not affect children, and it is extremely rare in adults under 40 years of age. The people most affected are those age 65+.[42] There is some evidence, again from the study based on the large-scale US SEER dataset, that there is an earlier onset of myeloma in black people. In this study, which examined patients during the period of 1973-2005, the median age at diagnosis was 66 years in black people and 70 years in white people. In other words, black people were developing myeloma approximately four years earlier.[39] Figure 11 shows the incidence of myeloma at specific ages in the UK population. There are no comparative UK data by race and age: this is therefore a further gap in the evidence that does need to be addressed.

Figure 11: Incidence of myeloma at specific ages: Rates per 100,000 population UK, 2009-2011



Source: Cancer Research UK [43]

4.9 **Gender:** Men are more likely to be diagnosed with myeloma than women. In 2012 in England, for example, out of 4,190 new diagnoses, 2,361 were men and 1,829 were women.[1] When this is age-standardised to account for the differences in age structure over time or over geographical areas, the rate becomes 9.0 per 100,000 population for men, and 6.7 per 100,000 for women. In other words, the excess risk burden for myeloma among men is a factor of 1.34.[1]

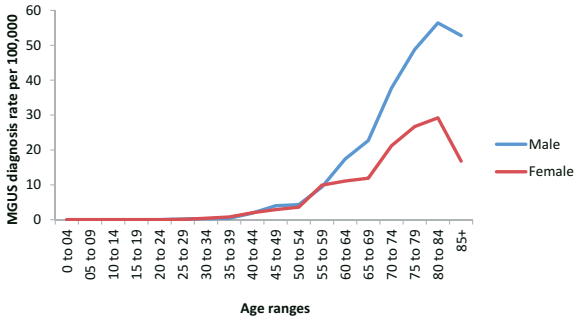
4.10 Data on the relative risk burden of myeloma for black men and white men, and black women and white women are scarce. The most recent data are for 2010, and once again come from the US SEER Cancer Statistics review.[38] This shows very clearly the significantly greater incidence of myeloma in men compared with women, in black men compared with white men, and in black women compared with white women. The data also show that black men have a higher myeloma risk burden than black women, and the highest risk overall. In addition, black men have a higher mortality rate than black women, and the highest mortality rate overall. It is important to make clear that mortality measures the frequency of the occurrence of death, and is partially dependent on the incidence of myeloma, while the survival rate is not. Therefore, the fact that higher mortality is observed in the black population is due to the fact that myeloma is more common in the black population, regardless of better observed outcomes overall.

4.11 **MGUS and progression to myeloma:** MGUS (monoclonal gammopathy of undetermined significance) which precedes myeloma, occurs in otherwise healthy people, causes no symptoms, and progresses to myeloma at a rate of about 1% per year. The prevalence of MGUS has been found to be twice as high in black Ghanaian men as in white people.[44] An analysis of MGUS prevalence in 14 studies showed that it is significantly more prevalent in black people (5.9% – 8.4%) than in white people (3.0% – 3.6%); more generally represented as an approximately two-fold difference.[45,46] Obesity and race are independently associated with MGUS. There is no association between socioeconomic status and incidence of MGUS or myeloma.

4.12 The incidence of MGUS in the UK, like that of myeloma, is not well documented by race. The best data are from the Haematological Malignancy Research Network (HMRN) and cover the former adjacent UK Cancer Networks of Yorkshire and the Humber, and Yorkshire Coast. The pattern of MGUS diagnoses (Figure 12) is broadly similar to that of myeloma. A major limitation again is that the data are not disaggregated by race, and this is a further gap in the evidence that needs to be addressed.

4.13 The higher risk of myeloma in the black population may be the result of the higher prevalence of MGUS, as there are no data to suggest that black people have a higher rate of progression from MGUS to myeloma.[47] This suggests that race-related susceptibility to MGUS and myeloma could be genetic, but in the absence of data this is speculative and therefore requires further investigation.

Figure 12: Incidence of MGUS at specific ages: Rates per 100,000 population UK, 2004-2010 (data from HMRN region of Northern England)



Source: Cancer Research UK [43]

Myeloma incidence and mortality rates per 100,000; US 2010

	White males	Black males	White females	Black females
Incidence rates	7.6	17.9	4.6	11.1
Mortality rates	3.9	7.8	2.4	5.5

Epidemiological Evidence – Key Points

1. Black people in the UK are 2-3 times as likely as white people to be diagnosed with myeloma or to have MGUS (monoclonal gammopathy of undetermined significance).
2. Myeloma is a disease of the over-50s, with mortality peaking at about 80 years of age.
3. Black people presenting with myeloma are on average four years younger than white people.
4. Black men have a higher incidence of myeloma than any group, and the highest mortality rate.
5. MGUS is associated with race and obesity, and is unrelated to social deprivation.

"Clinical trials, informed by epidemiological studies, are important to understanding the genomic or epigenetic characteristics of myeloma, the therapies that work best and the populations and circumstances in which they do so".

5. Multiple myeloma and clinical research

"Black African and black Caribbean people are consistently under-represented in clinical trials of drugs and medical procedures. It is important to address this to inform stratified medicine. A stratified medicine approach, detecting specific gene mutations in cancer cells of individual myeloma patients, has good prospects for identifying the most appropriate treatment pathways in populations which are particularly susceptible".

5.1 **Clinical trials and their importance to multiple myeloma in black populations:** The key factors in the biology of myeloma in black people, as for any other racial group, are not known. Clinical trials, informed by epidemiological studies, are important to understanding the genomic or epigenetic characteristics of myeloma, and are important in determining which therapies work best and the populations and circumstances in which they do so. As such, clinical trials provide the testing ground for safety and efficacy before the introduction of novel drugs, medical devices and procedures. Clinical Trials of Investigational Medicinal Products (CTIMP) involve the testing of new drug therapies, medicines and the use of placebos, and are governed by the Medicines and Healthcare Products Regulatory Agency (MHRA). At the time of writing (June 2015), 102 myeloma clinical trials are registered on the National Institute for Health Research Clinical Trials Gateway, as currently running in 125 locations across the UK. They are funded by various agencies including Myeloma UK, which itself runs a clinical trial network at 30 hospitals. Within the network are nine trials across the UK in Nottingham, Leeds, London, Manchester, Birmingham, Sheffield, Oxford, Southampton and Cardiff.

5.2 **The genomic or epigenetic characteristics of multiple myeloma and the importance of recruiting black people to clinical trials:** As preceding sections have made clear, black people have twice the risk of myeloma. While recent epidemiological evidence points to a survival advantage among black people, they do have the highest rate of mortality as the disease is more prevalent within the black population. There is a need for further research to understand the extent to which black people are recruited to myeloma trials, as their participation is important to an understanding of the biology of the disease. The current literature identifies a number of issues that relate to clinical trials from the perspective of healthcare professionals, and black and minority ethnic groups. An understanding of the epidemiology of myeloma is inseparable from improving the agenda for service development, and clinical research is integral to this.

5.3 **Barriers to participation of black and minority ethnic groups in clinical trials:** There is consensus in the literature about the importance of increasing race and ethnic diversity in clinical trials to enhance the public benefit of medical interventions.[48] A body of evidence in the US, and some from the UK suggests that the term clinical trial conjures up negative historical experiences about ethical abuses in the cultural memory of black people. These negative past experiences are seen as having given rise to a factually based distrust of the scientific community.[§, 49-52] The factors shaping participation are, however, far more complex, and further evidence suggests that a lack of access appears to play a more pivotal role. In the US, the Coalition to Eliminate Disparities and to Research Inclusion in Clinical Trials (CEDRICT) has published evidence based on visits to 20 US cities since 2009, and interviews and focus groups with 50,000 African Americans. The majority of participants, 58%, said that they did not participate in clinical trials because they had not heard of them, and 92% of participants in the study said that they would participate in clinical trials if they had more information about them.[53]

§ The notorious Tuskegee Syphilis Study carried out between 1932 and 1972 by the United States Public Health Service is one example. In that study, poor black sharecroppers in Alabama were recruited to a clinical trial to study the natural progress of syphilis. While the study was in progress, penicillin was discovered to treat syphilis but the study continued and the men were not treated with penicillin that could have cured them.

5.4 Similarly, a meta-analysis of clinical trials explored the question of whether black people were less likely than white people to participate in clinical trials.[54] The study found that black people were as willing to participate as white people, but that they were not asked to do so. A fairly recent study found that the legacy of the Tuskegee project, while engendering fear, did not inhibit minority groups from participating in clinical trials, despite prevailing views that it does.[55] The study also found that while black people are in general more distrustful of trials, this distrust does not influence their willingness to participate. Where black people have a congenial and trusting relationship with healthcare professionals and clinical researchers, they are more likely to participate in a clinical trial.[56]

5.5 A study of the attitudes of clinicians in the US found that clinicians were more likely to have negative impressions of black patients compared with white patients, and that they were likely to believe that black patients were less intelligent and less educated than white patients. This study also found that clinicians were biased in terms of who they thought would be able to comply with, and adhere to, difficult clinical trial regimes and protocols.[57] Another study showed that regardless of race, men with higher levels of education were more likely to take part in clinical research than men without a high level of education.[58] In the UK, evidence presented to a House of Commons Science and Technology Select Committee examined the question of clinical trials. While the Committee did not specifically address representation of black and minority ethnic groups, it did explore barriers generally to participation.[59] The Committee heard evidence that healthcare professionals were relatively uninformed about clinical trials, and had no tailored resources to support conversations with diverse patient groups. The evidence that the Committee received also suggested that 91% of hospitals had no public information available about clinical trials.

5.6 The Collaboration for Improving the Delivery of Ethnically Appropriate Research Services and Policy (IDEA) at Warwick University, at its 2011 Annual Scientific Meeting, pointed to the under-representation of ethnic minorities in clinical trials. The IDEA argues that exclusion is often on the basis of the greater financial burden of including minority ethnic groups, and this is because minority ethnic populations are seen as *'hard to reach'.*[60] A recent retrospective analysis of 17 prostate cancer clinical trials in 6 countries over the past 20 years, mentioned here because of the similarities in its higher incidence in black men compared to white men, found that black and minority ethnic groups were consistently under-represented with only 5% of the studied patient population engaging black men.[61] The same authors examined the outcome of trials submitted to the Federal Drug Administration over a 20-year period and found that minority ethnic groups were consistently under-represented in key prostate cancer trials and called for effective measures to improve enrollment among this group.[62] It is important to explore whether there are barriers to the participation of black people in myeloma trials from the perspective of healthcare professionals, and from the perspective of the black community.

5.7 **Moving towards diversity and inclusion in clinical trials:** The National Cancer Equalities Initiative noted in its 2010 report on reducing cancer inequality that it was in the process of engaging in discussions with the NCIN and research funders, through the National Cancer Research Institute (NCRI). This was to prioritise additional research in equality areas. The National Cancer Research Network (NCRN) was to be asked to explore inequalities in access to clinical trials, and whether steps were needed to improve access in any patient group. It was recognised that there might need to be improvements in information flow before this was possible. The later report from the NCRI, however, stated only that older people, people with rare diseases, and people from black and minority ethnic groups tend to be less well represented.[63]

5.8 The report recommended that principal investigators and participating centres need to consider how messages are communicated to people whose principal language is not English and who have varying levels of literacy. The report also recommended that patients should be supported to attend another cancer centre beyond their catchment area, if an appropriate trial is unavailable locally. Groups of providers could work together to deliver access to clinical trials by including smaller centres; underpinned by new technology and innovative ways of

working. The report further recommended that research funders should work with principal investigators of large-scale clinical trials to assess whether or not the demographics of trial participation reflects the wider population of people affected by cancer.

5.9 **Stratified medicine benefiting all people with multiple myeloma:** At the present time, all people diagnosed with myeloma are treated according to a standard sequence of therapies. The major advances in human genomics over the last ten years has, however, brought with it the realisation that individual patients or groups of patients may not necessarily respond to therapies in the same way or to the same extent. There is now greater understanding of the human genome and this is beginning to open the way for more targeted treatments. The House of Lords' 2009 report on Genomic Medicine identified as a priority, patients who are more likely to benefit or to experience an adverse effect from a particular therapy.[64] This is precisely the concept of stratified medicine: an approach that targets treatment specifically to sub-populations of patients who are more likely to benefit from, or less likely to be harmed by, a particular treatment.[65] According to its 2011 Strategy for Cancer, the Department of Health has begun work with its partners to identify how a stratified approach could be used to good effect for cancer patients. The cross-departmental Human Genomics Strategy Group was set up in response to the House of Lords' report and it is important that equality implications are considered as the group is overseeing the integration of genomic medicine into mainstream healthcare.

5.10 Stratified medicine could be employed in myeloma to identify gene mutations in the cancer cells. It is likely that as the technologies develop, multiple tests could be carried out on tumours. It is also now known that most tumours result from a number of mutations, so the effectiveness of one therapy could be assessed and then indicate its effectiveness in another type of cancer. Ideally this might have cost-effective implications for the NHS, if pathology laboratories can gather sufficient evidence. The Department of Health anticipates that the technology, the service, and its outcomes should be routine within 5-10 years. Patients will benefit by faster entry to a treatment pathway that is more likely to be successful for them, rather than spending time on less effective treatments. They will also be spared the side effects of treatments that are not effective for them. Myeloma could clearly benefit from stratified medicine, especially the black population that, as this research has illustrated, has a particular susceptibility to the disease and a higher mortality rate.

5.11 In the UK, research is already under way to identify the key genetic faults driving the growth of the most common forms of cancer, involving the Department of Health, industry and medical academic partners.[66] The ultimate aim will be to enable use of genetic sequencing techniques in routine clinical practice. The interim benefits will include the creation of a national quality assurance scheme and a significant contribution to genomic and informatics facilities at NHS sites.[67] There is, as yet, no global or European pharmacogenomics database, and the World Health Organization recommends establishment of a European research network and a European catalogue of pharmacogenomics datasets with a harmonisation programme.[65] Databases must keep pace with genomics technology, and data harmonisation is essential for robust, structured analysis.

Multiple Myeloma and Clinical Research – Key Points

1. The key factors in myeloma biology for black people are not known. Inclusive clinical trials informed by epidemiological studies are important in understanding the genomic or epigenetic characteristics of myeloma, and in service development.
2. There is a need for further research to understand the extent to which black people are recruited to myeloma trials, as their participation is important to understanding the biology of the disease.
3. Research funders should work with principal investigators of large-scale clinical trials to assess whether or not the demographics of trial participation reflect the wider population of people affected by cancer.
4. The major advances in human genomics over the last ten years have brought the realisation that individual patients or groups of patients may not necessarily respond to therapies in the same way or to the same extent.
5. Stratified medicine could be employed in myeloma to identify gene mutations in the myeloma cells. This has potential benefits for the black population, which has a particular susceptibility to the disease.

"There have been major advances in human genomics over the last ten years. This has brought with it, the realisation that individual patients or groups of patients may not necessarily respond to therapies in the same way or to the same extent".

6. Conclusions and recommendations

6.1 **The Epidemiology of multiple myeloma in black populations in the UK:** Myeloma disproportionately affects the black population, and particularly black men. Black people are 2-3 times more likely than white people to develop myeloma, and do so on average four years younger than white people. Black people also have a higher rate of mortality.

6.2 **The policy context for health services:** The principle of equality is embedded in law and in the NHS Constitution. The NHS has pledged to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population. The current cancer strategy acknowledges the special difficulties of rare types of cancer, but it focuses on cancers that are preventable through lifestyle. Many significant government initiatives have made substantial progress in identifying needs and gaps in service provision, notably the National Cancer Equality Initiative. However, not enough attention has so far focused on the early detection of myeloma in black people, on understanding the reasons for its disproportionate presentation in this population group, and monitoring the recruitment of black people to myeloma clinical trials.

6.3 **The implications of changing demographics:** As myeloma is a condition of older people, it is important to recognise that as the UK population ages as a whole, there will be an increase in its prevalence in the black population as its second generation also ages. This should be ringing alarm bells among those responsible for services for people with myeloma. Diagnosis and treatment of myeloma, in general, has benefited immensely in the last ten years from the results of clinical trials and primary research, especially in the area of genomics. The challenge for the future is to monitor coverage of black populations in myeloma clinical trials to ensure that this group, which has the highest risk burden of the disease, is included.

6.4 **Existing health service provision:** Black and minority ethnic groups have been found to experience poorer health than others, and also poorer access to services. Specifically in relation to cancer, the National Cancer Patient Experience Survey identified the need for more effective communication from GPs with minority ethnic patients and better GP diagnostic skills. It also called for examination of the quality of care received by these patients, the number of GP consultations before referral, and the proportion of cancer patients who present as an emergency. The 2014 survey by BME Cancer Voice also found a poorer overall patient experience among black and minority ethnic groups.

6.5 Cancer patients who initially entered treatment through an emergency department route commonly had a more negative perception of services compared with those who began treatment following a planned pathway referral, according to the 2014 Patients Survey. As patients who present as an emergency are likely to have a poorer outcome than those who have received earlier care from a GP, this reinforces the need for diagnosis as early as possible in the course of illness. This is particularly important for patients with rare cancers, who have reported poorer care.

6.6 Analysis of the health outcomes in the five local authorities has shown a focus on detection and treatment of coronary heart disease; respiratory problems, particularly chronic obstructive pulmonary disease and asthma, and cancer, that is, the preventable long-term conditions, which affect the largest numbers of people, in line with overall national cancer strategy. Wider attention is needed to rare types of cancer, like myeloma, which disproportionately affect black and minority ethnic populations. Detailed race and ethnicity of residents receiving healthcare in primary care or hospitals is still not fully recorded and this hampers analysis. Finally, greater cultural awareness and sensitivity from healthcare providers could enable more effective communication, and therefore the earlier detection and treatment of myeloma.

6.7 **Policy initiatives for future service development:** The policy initiatives, which could help to address the issues arising from this research, are set out in the following recommendations.

Recommendations

1. The collection and interpretation of comparative epidemiological data on myeloma and MGUS, including race-disaggregated data, is in need of improvement. More detailed recording of race and ethnicity in Hospital Episode Statistics and also in primary care would enable a more comprehensive understanding of myeloma by race, age, gender and ethnicity.

2. Race and ethnicity should be consistently taken into account in clinical research on myeloma in order to inform the development of clinically and culturally appropriate healthcare services. There is a need to explore the experience of black and minority ethnic groups in myeloma clinical trials, by supporting the continuing dialogue with patient groups, and the voluntary and community sector.

3. Molecular studies should be commissioned to understand the difference in diagnosis, survival and mortality patterns in myeloma between black and white racial groups, and to understand the efficacy of treatments as part of the development of personalised management. It is important also that equality issues are considered within the remit of the cross-departmental Human Genomics Strategy Group set up in response to the House of Lords' 2009 report on genomic medicine.

4. A post-research task group should be established to take forward recommendation 3 above in relation to molecular studies.

5. Wider attention should be given by local authorities, clinical commissioning groups and other public sector partners, within the scope of their responsibilities under the Health and Social Care Act, 2012, and the Equality Act, 2010, to the specific health needs of black and minority ethnic groups. The focus at the local level should also take account of the needs of the black and minority ethnic population, particularly with rare diseases such as myeloma.

Appendices

Appendix 1: Literature searches

Clinical and epidemiological survey

Search terms used for PubMed searches were:

"multiple myeloma"[MeSH Terms] OR ("multiple" [All Fields] AND "myeloma"[All Fields]) OR "multiple myeloma"[All Fields] OR "myeloma"[All Fields]) AND ("african continental ancestry group"[MeSH Terms] OR ("african"[All Fields] AND "continental"[All Fields] AND "ancestry"[All Fields] AND "group"[All Fields]) OR "african continental ancestry group"[All Fields] OR "african"[All Fields]

"multiple myeloma"[MeSH Terms] OR ("multiple" [All Fields] AND "myeloma"[All Fields]) OR "multiple myeloma"[All Fields] OR "myeloma"[All Fields]) AND ("african continental ancestry group"[MeSH Terms] OR ("african"[All Fields] AND "continental"[All Fields] AND "ancestry"[All Fields] AND "group"[All Fields]) OR "african continental ancestry group"[All Fields] OR "black"[All Fields] OR "african americans"[MeSH Terms] OR ("african"[All Fields] AND "americans" [All Fields]) OR "african americans"[All Fields]

"multiple myeloma"[MeSH Terms] OR ("multiple" [All Fields] AND "myeloma"[All Fields]) OR "multiple myeloma"[All Fields] OR "myeloma"[All Fields]) AND ("ethnic groups"[MeSH Terms] OR ("ethnic"[All Fields] AND "groups"[All Fields]) OR "ethnic groups"[All Fields] OR "ethnic"[All Fields]

"multiple myeloma"[MeSH Terms] OR ("multiple"[All Fields] AND "myeloma"[All Fields]) OR "multiple myeloma"[All Fields] OR "myeloma"[All Fields]) AND ("west indies"[MeSH Terms] OR ("west"[All Fields] AND "indies"[All Fields]) OR "west indies"[All Fields] OR "caribbean"[All Fields] OR "caribbean region"[MeSH Terms] OR ("caribbean"[All Fields] AND "region"[All Fields]) OR "caribbean region"[All Fields]

Clinical trials

Search terms used in relation to clinical trials were:

"discrimination (psychology)"[MeSH Terms] OR ("discrimination"[All Fields] AND "(psychology)"[All Fields]) OR "discrimination (psychology)"[All Fields] OR "discrimination"[All Fields]) AND ("neoplasms"[MeSH Terms] OR "neoplasms"[All Fields] OR "cancer"[All Fields]) AND care[All Fields]

"clinical trial"[Publication Type] OR "clinical trials as topic"[MeSH Terms] OR "clinical trials"[All Fields]) AND ("african continental ancestry group"[MeSH Terms] OR ("african"[All Fields] AND "continental"[All Fields] AND "ancestry"[All Fields] AND "group"[All Fields]) OR "african continental ancestry group"[All Fields] OR "black"[All Fields] OR "african americans"[MeSH Terms] OR "african"[All Fields] AND "americans"[All Fields]) OR "african americans"[All Fields]) AND ("residence characteristics"[MeSH Terms] OR ("residence" [All Fields] AND "characteristics"[All Fields]) OR "residence characteristics"[All Fields] OR "communities"[All Fields]

("clinical trial"[Publication Type] OR "clinical trials as topic"[MeSH Terms] OR "clinical trials"[All Fields]) AND ("BME"[Journal] OR "bme"[All Fields]) AND ("residence characteristics"[MeSH Terms] OR ("residence"[All Fields] AND "characteristics" [All Fields]) OR "residence characteristics"[All Fields] OR "communities"[All Fields])

"african continental ancestry group"[MeSH Terms] OR ("african"[All Fields] AND "continental"[All Fields] AND "ancestry"[All Fields] AND "group"[All Fields]) OR "african continental ancestry group"[All Fields] OR "black"[All Fields] OR "african americans"[MeSH Terms] OR ("african"[All Fields] AND "americans"[All Fields]) OR "african americans"[All Fields]) AND ("men"[MeSH Terms] OR "men"[All Fields]) AND ("health services accessibility"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields] AND "accessibility"[All Fields]) OR "health services accessibility"[All Fields] OR ("access"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "access to health care"[All Fields]

"african continental ancestry group"[MeSH Terms] OR ("african"[All Fields] AND "continental"[All Fields] AND "ancestry"[All Fields] AND "group"[All Fields]) OR "african continental ancestry group"[All Fields] OR "black"[All Fields] OR "african americans"[MeSH Terms] OR ("african"[All Fields] AND "americans"[All Fields]) OR "african americans"[All Fields]) AND ("residence characteristics"[MeSH Terms] OR ("residence"[All Fields] AND "characteristics"[All Fields]) OR "residence characteristics"[All Fields] OR "communities"[All Fields]) AND access[All Fields] AND ("delivery of health care"[MeSH Terms] OR ("delivery"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "delivery of health care"[All Fields] OR "healthcare"[All Fields]

"african continental ancestry group"[MeSH Terms] OR ("african"[All Fields] AND "continental"[All Fields] AND "ancestry"[All Fields] AND "group"[All Fields]) OR "african continental ancestry group"[All Fields] OR "black"[All Fields] OR "african americans"[MeSH Terms] OR ("african"[All Fields] AND "americans" [All Fields]) OR "african americans"[All Fields]) AND ("men"[MeSH Terms] OR "men"[All Fields]) AND ("empathy"[MeSH Terms] OR "empathy"[All Fields]

Appendices

Appendix 2: Demographic and health data relating to the Joint Strategic Needs Assessments of five unitary authorities

Key demographic indicators for five unitary authorities

	Lambeth (London)	Lewisham (London)	Birmingham City (West Midlands)	Nottingham City (East Midlands)	Stockton-on-Tees (North West Region)
Population, 2012	310,000[17]	282,000[18]	1,085,000[19]	309,000[20]	192,000[21]
Ethnicity, 2011[14]	25.9% black [cf. 3.4% England]	27.16% black [cf. 3.4% England]	8.98% black [cf. 3.4% England]	7.3% black [cf. 3.4% England]	0.6% black [cf. 3.4% England]
Black population breakdown, 2011[14]*	BA: 11.61% BC: 9.53% OB:4.77%	BA: 11.61% BC: 11.18% OB: 4.37%	BA: 2.79% BC: 4.44% OB: 1.75%	BA: 3.23% BC: 3.07% OB: 0.96%	BA: 0.49 BC: 0.04 OB: 0.06
Deprivation rank in England[68]	29th most deprived LA out of 326 LAs in England	31st most deprived	9th most deprived	20th most deprived	75th most deprived
Deprivation, % people in this area living in 20% most deprived areas in England, 2010	36.6%[17] [cf. England: 20.4%]	36.5%[18] [cf. England: 20.4%]	56.2%[19] [cf. England: 20.4%]	52.0%[20] [cf. England: 20.4%]	29.5%[21] [cf. England: 20.4%]

* BA = black African; BC = black Caribbean; OB = Other Black British

Key health indicators for five unitary authorities

	Lambeth (London)	Lewisham (London)	Birmingham City (West Midlands)	Nottingham City (East Midlands)	Stockton-on-Tees (North West Region)
Main health issues	Circulatory and respiratory problems, also lung cancer (males)[23]	Circulatory and respiratory problems, also lung and colon cancer (males)[24]	CHD, COPD, cancers esp. lung, colorectal and prostate in males[25]	Circulatory diseases esp. CHD, cancers esp. lung cancer[26]	High levels of heart disease, cancer and respiratory diseases[27]
Life expectancy at birth 2011-2013	Male: 78.4 yrs; Female: 83 yrs [cf. England: Male: 79.4 yrs; Female 83.1 yrs]	Male: 78.7 yrs; Female: 83.0 yrs [cf. England: Male 79.4 yrs; Female 83.1 yrs]	Male: 77.6 yrs; Female: 82.2 yrs [cf. England: Male 79.4 yrs; Female 83.1 yrs]	Male: 77.0 yrs; Female: 81.7 yrs [cf. England: Male 79.4 yrs; Female 83.1 yrs]	Male: 78.4 yrs; Female: 82.3 yrs [cf. England: Male 79.4 yrs; Female 83.1 yrs]
Life expectancy at age 65 yrs 2011-2013[69]	Male: 18.0 yrs; Female: 21.6 yrs [cf. England: Male: 18.67 yrs; Female: 21.13 yrs]	Male: 18.1 yrs; Female: 21.1 yrs [cf. England: Male: 18.67 yrs; Female: 21.13 yrs	Male: 17.9 yrs; Female: 20.7 yrs [cf. England: Male: 18.67 yrs; Female: 21.13 yrs]	Male: 16.9 yrs; Female: 20.6 yrs [cf. England: Male: 18.67 yrs; Female: 21.13 yrs]	Male: 18.2 yrs; Female: 20.5 yrs [cf. England: Male: 18.67 yrs; Female: 21.13 yrs]
Life expectancy at age 75[29]	Male: 11.5 yrs; Female: 13.8 yrs [cf England: Male: 11.5; Female: 13.3 yrs]	Male: 11.5yrs; Female: 13.4 yrs [cf England: Male: 11.5; Female: 13.3 yrs]	Male: 11.3 yrs; Female: 13.2 yrs [cf England: Male: 11.5; Female: 13.3 yrs]	Male: 10.6yrs; Female: 13.1 yrs [cf England: Male: 11.5; Female: 13.3 yrs]	Male: 11.5yrs; Female: 12.9 yrs [cf England: Male: 11.5; Female: 13.3 yrs]
% 1-year survival from all cancers (2011 diagnoses, age 15-99)	65.33% [cf. England: 68.2%][23]	65.99% [cf. England: 68.2%][24]	68.10% [cf. England: 68.2%][25]	65.12% [cf. England: 68.2%][26]	65.69% [cf. England: 68.2%][27]
Under 75 mortality rate for cancer (age-standardised per 100,000 <75s)	159 [cf England: 146][70]	159 [cf England: 146][18]	162 [cf England: 146][19]	162 [cf England: 146][20]	174 [cf England: 146][21]
Health-related quality of life (HRQoL) for pple with long-term conditions.[71,*]	0.748 [cf. England: 0.743]	0.745 [cf. England:0.743]	0.712 [cf. England: 0.743]	0.701 [cf. England: 0.743]	0.708 [cf. England: 0.743]

* Directly standardised average health status score (EQ-5D™) for individuals aged 18 and over who identify themselves as having a long-term condition, weighted for design and non-response

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For further information contact:

Email: info@basilskyersfoundation.org

Website: www.basilskyersfoundation.org

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