DEVELOPING HEALTH LITERACY AMONG CARIBBEAN AND AFRICAN FAITH LEADERS TO INFLUENCE DECISION MAKING AT STRATEGIC LEVELS

OCTOBER 2018

MARY SEACOLE TRUST

FAYE BRUCE
SENIOR LECTURER NURSING
MANCHESTER METROPOLITAN UNIVERSITY
MARY SEACOLE AWARDEE 2017/2018

Health Education England NHS
Unite the UNION in HEALTH
CPHVA
Royal College of Nursing
The Royal College of Midwives
Manchester Metropolitan University
CAHN Caribbean & African Health Network Greater Manchester

ACKNOWLEDGEMENTS

It has been such a pleasure to work on this project. This study has been driven by a piece of work I undertook with the Caribbean and African Community in Greater Manchester that focused upon the hidden factors affecting poor cardiovascular disease outcomes. I want to start by saying thank you to all the participants including directors of the Caribbean and African Health Network (CAHN) Greater Manchester (See appendix H for more information). They have inspired, supported, challenged and enabled me to deliver on this initiative. It was from this organisation that I was able to reach the faith community and gain so much interest in developing the project.

My thanks continue to the faith leaders and the speakers that gave up their time to take part in the study. Without your contribution and commitment, this study could not have happened. Gratitude goes to the Greater Manchester Health and Social Care Partnership namely Maqsood Ahmed who helped support this project from the outset, Manchester Foundation Trust and Manchester Metropolitan University who supported this study and provided me with the space to maximize on the project's outcomes.

My PhD supervisor Dr Ornette has been an incredible tower of support and he continues to inspire and help me to polish ideas into something tangible. Finally, and most importantly, my mum and dad have been with me on every step of my journey offering support and I want to thank them sincerely. My family, my children have been incredibly patient as they understand the need for mum to do all she can to improve the health of the Caribbean and African community

Thank you to the Mary Seacole committee for enabling me to deliver on this project, I hope that I can utilize your support to further develop this piece of work.

CONTENTS

1. ABSTRACT/PROJECT SUMMARY

The health inequalities across a number of health conditions within the Caribbean and African community is well evidenced. There is variation in access to services; inappropriate and untimely treatments and culturally insensitive practices when health services are provided to Black people across the UK.

Alongside the experiences identified above, there is evidence of limited involvement of Caribbean and African people at senior decision-making levels of our health system. This results in unheard voices from this community to influence policy, practices and provide appropriate health services.

A significant number of the black population belong to a church or have some affiliation to a church. As a result, the purpose of this project was to evaluate whether the framework of a one-day community leadership programme would be effective in developing the health literacy of faith leaders to enable them to be advocates and engage in decision making at senior levels of the health and care system.

Twenty-seven faith leaders attended the one-day workshop which was evaluated using two focus groups. Semi-structured interviews were used to gather data from five strategic sector leads who presented on the day. The data was thematically analysed to generate four themes from Faith leaders and two themes from Strategic sector leads.

Faith leader's themes identified the lack of education for health improvement; inequitable resource allocation; value and richness of health and healing and learning from each other. Among statutory leads, two common themes acknowledged a lack of understanding of the importance of faith and partnering opportunities with Black Faith leaders.

Overall, this project found wide variation of knowledge from faith and strategic leaders that compromise the ability to articulate the needs of their congregants and impact change at the strategic and operational levels.

Based on the findings, this programme provides a real opportunity to address a number of health and wellbeing concerns identified in the 5 Year Forward View (5YFV) (2014). This can be delivered through the use of faith leaders as gatekeepers and as agents of change. This would involve faith leaders working with strategic agencies so that they can equip each other with knowledge to improve the health of hundreds of congregants they have access to on a regular basis.

'Be sure you know the condition of your flocks, give careful attention to your herds'. Proverbs 27:23 New International Version

2. INTRODUCTION

2.1. BACKGROUND AND CONTEXT

The last seven decades has seen a surge of church openings with significant but not exclusive attendance of people from Caribbean and African backgrounds, (Census, 2011) in England and Wales. This study is carried out in light of poor health outcomes across the Caribbean and African community, and the move towards mixed modes of care delivery within the context of the 5YFV (2014) and 5YFV Next Steps (2017).

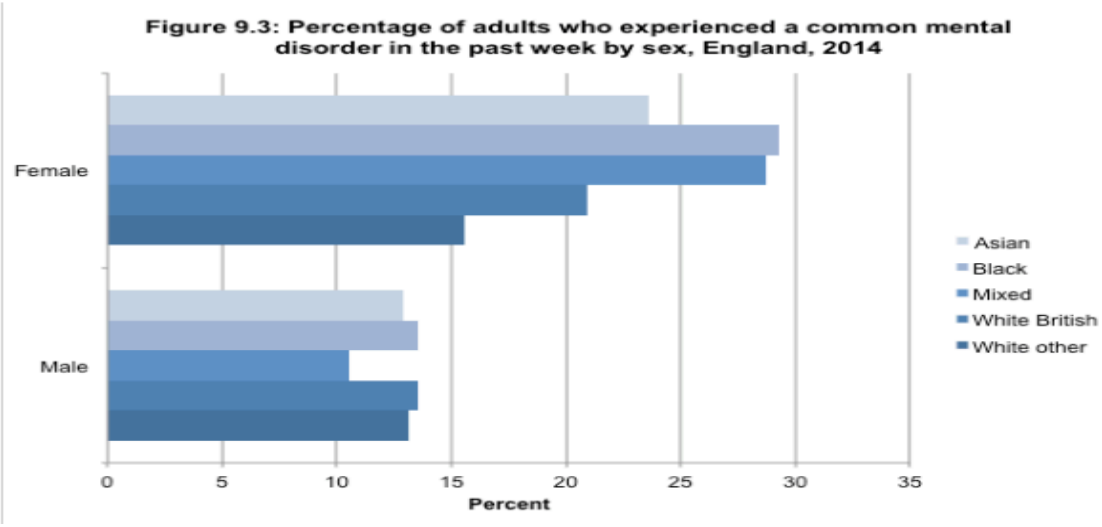
This chapter identifies relevant national and faith policy whilst drilling down to a local Greater Manchester landscape within the context of Devolution.

2.2 HISTORICAL OVERVIEW OF CARIBBEAN AND AFRICAN PEOPLE IN THE UK

Migrants from the Caribbean islands have existed in the UK for several decades, however more started to arrive in large numbers 70 years ago. Since the 22nd June 1948, the number of people from the African and Caribbean diaspora has increased significantly from the 492 immigrants that arrived on SS Windrush to now over 3.7% of the 66.57 million population; this number includes those that identify as Caribbean and African mixed heritage (Census, 2012).

The numbers of black people were largely from the Islands of the Caribbean, however, people arriving directly from African countries have increased significantly in the last few decades and now make up 3% of the Black population here in the UK (Census, 2011). It is important to appreciate that Black African and African Caribbean communities are not a homogeneous group but include people from a range of countries with diverse cultural, religious, language and socio-economic backgrounds and political challenges (Ahmad and Bradby, 2007). However, in large urban cities across England, there is a clear demographical concentration of particular ethnic groups including those of Caribbean and African heritage that reside in areas of relative disadvantage. Housing, employment, education and living standards, are significantly worse in these areas resulting in health disparities between the rich and the poor (Becares, 2011).

Although there are these differences between the groups, Caribbean and African people whether born in England or have lived here as immigrants from abroad, their chances of good health and wellbeing is remarkably reduced in comparison to the majority population (Agyemang, 2003, Bhopal, 2007, Becares, 2011, Bowes, 2015, Cabinet Office, 2017). Caribbean and African people are disproportionately affected by health problems and face significant inequities in treatment and care. Some individuals may be less likely to access or engage in mainstream health services that can help to prevent ill health and promote wellbeing.



Race Disparity Audit - Cabinet Office (2017)

2.3 NATIONAL POLICY CONTEXT

Since the inception of the UK National Health Service (NHS) in 1948, the UK has evolved to become one of the largest and best healthcare systems globally (Schneider, 2005). However, the health care system has been challenged to meet the demand of its founding principles of free health care for all at the point of need and as a result undergone major reforms. A number of reorganizations and restructures have occurred over the last seven decades including the creation of the internal market in 1990 that enabled the NHS and Community Care Act (1990) control over their own budgets. The application of market principles through a mixed economy of care opened up the health service to competition by creating the purchaser provider split inviting the different sectors to provide services. In the last 18 years, there has been an unprecedented number of reforms in the UK resulting in the introduction of a range of health policies and strategies. Long term pressures on the public sector has resulted in a focus upon active social responsibility in

the governments public service modernization agenda, (Aspinall and Jacobson, 2004) and there has been an emphasis on the need to reduce health inequalities by engaging with local communities. The aim of these new ways of working was to promote participation and engagement with health services (Marmot, 2010).

The 5YFV (2014) and 5YFV next steps (2017) is a strategic vision that describes a set of principles to support new models of care to address the gaps in health and wellbeing services. It recognises that the NHS would not be sustained without this vision. This vision includes a deeper focus upon prevention through integrated community and partnership working with the voluntary sector, local agencies and the NHS to address the wider determinants of health. The NHS 5YFV (2014) highlights the need for closer and more efficient working across these sectors to reduce the demand on primary and secondary care services that are costly and resource intensive.

2.4 GREATER MANCHESTER AND IT'S LOCAL POLICY CONTEXT

Alongside the national context outlined above, there is also a local policy landscape with a distinctive uniqueness and concentration tailored to Greater Manchester residents. As with national policy to address health inequalities, a key priority for Greater Manchester is to tackle some of the worst health outcomes and health inequalities across England, (Greater Manchester Combined Authority, 2015)

Despite being the seat of the revolutionary uprising in the 19th century and a having a history of campaigning for greater autonomy in the United Kingdom, the Greater Manchester (GM) regions consist of a heterogeneous mix of striking advantage amidst significant areas of disadvantage in the country. GM is one of the most deprived regions with lower than average life expectancy in England with three clinical commissioning groups out of its ten classified as one of the 10% most disadvantaged in the country, (ONS, 2015). The disparities across the region has presented notable socio-economic inequality and according to the Index of Multiple Deprivation, (DCLG, 2015), over a third of the 2.8 million people of Greater Manchester (36%) live in regions ranked among the

bottom 20% nationally.

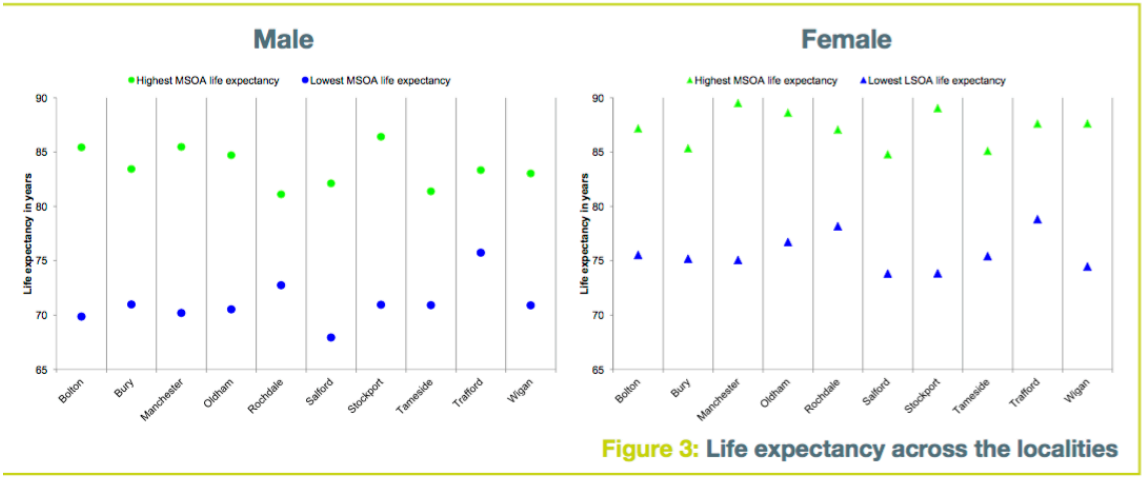


Figure 3: Highest and lowest life expectancies within each local authority

Changes in Central Government have provided local areas with the ability to take much more control over decision making for their region**.** Greater Manchester's "Taking Charge" Strategy (2015) sets out an ambitious approach to improving health and care in a region of England known for poor health and wellbeing. Polletta, (2014) highlights that democracy and localism gives people and communities a voice so that they can feel in control of their own destiny especially those that are seldom heard.

With a mandate to manage and make its own decisions, Greater Manchester is now responsible for delivering health and social care improvement to the 2.8 million people in the region. Greater Manchester Combined Authority's (GMCA) ambition is to develop mutual partnerships and joined up working with communities and across public services to prevent poor health and develop strategies to enable early intervention, for improved health outcomes.

2.5 FAITH AND HEALTH POLICY CONTEXT

Historically, religious institutions and health care provision have been inseparably linked. Religious institutions were influential in establishing the first hospitals and care facilities and as result of nationalization of the health service, faith institutions now have to re-invent themselves to gain their place back into the provision of health and care. Hospital chaplains have been part of the NHS infrastructure since hospitals were developed and are deemed to be an asset that supports the provision of care services, (Mowat, 2008). Although hospital chaplains are affiliated to different religions, patients or service users

sometimes call on their own faith leader for spiritual, religious and pastoral care when in hospital settings. Today, chaplains have been developed in to a recognized professional group and work with NHS staff to support and respond to the spiritual care needs of patients.

The health policy landscape recognises the importance of faith and advocates that spiritual care needs are available for patients especially in terminal illness. To support this policy, the Equality Act (2010) has religion as one of the protected characteristics and makes it clear that health bodies have a duty to ensure that spiritual, religious and pastoral needs of those using care services are met. Consequently, the Equality Act (2010) has bought increasing emphasis on the needs of commissioners and providers of health services to work with faith organisations to raise awareness of health prevention and treatment. In addition to this, the Health and Social Care Act (2012) gives Clinical Commissioning Groups (CCGs) the power to procure and commission voluntary and community sector initiatives at national, regional and local levels.

2.6 THE CARIBBEAN AND AFRICAN DIASPORA AND THE BLACK MAJORITY CHURCHES (BMC)

In the context of this report, a faith group will follow the defining concept of a faith-based organization - ‘any organisation that derives inspiration from and guidance for its activities from the teachings and principles of faith or from a particular interpretation or school of thought within a faith’ (Clarke and Jennings, 2008).

Faith is deeply entrenched in Caribbean and African culture. According to the Census (ONS, 2011), the church landscape is significantly diverse since the arrival of the Common Wealth Windrush migrants from the Caribbean in 1948 in post war Britain (Adedibu, 2012). Although the BMC were never meant to be exclusive to black people, the last seven decades has seen an influx of people from the Caribbean and African countries creating churches across major cities including Greater Manchester. This notoriously occurred as they were rejected from English churches and society at large when they arrived in the 50s & 60s. However, some Caribbean and African faith leaders came as missionaries (Aldred, 2007). Despite 90% attendance of ethnic minorities in congregations of the Church of England, only 1.1% of Bishops, archdeacons and Cathedral Deans are from an ethnic minority background in the General Synod of the Church of England (Kajumba, 2013).

Many of the immigrants brought with them their religious practices that adds to diversity of religious institutions which to this day consists of multiple ethnic groups. People from the African diaspora highlight that church attendance promotes a sense of community, belonging, ethnic identity and provide resources for the growth of the community (Taylor, Chatters, & Jackson, 2007). Although the BMC in the UK is unlike America where they adopt political activists' movements to address injustice, the BMC in the UK has grown significantly over the last decades and some faith leaders are recognized as national ecumenical partners.

Within the Caribbean and African community, faith groups are important stakeholders that form part of the voluntary and community sector and play a significant role in delivering services in the community (LGA 2014). They are often the place that people turn to for comfort and advice and as such faith leaders can play a large role in health and care. As such the BMC is strategically well placed to attract Caribbean and African people to address health and social care issues that have plagued the community over the decades. Despite this, in Manchester which has the highest concentration of BMC in GM, there is not one single contractual agreement between the BMC and CCG or other public sector provider to address heath inequalities.

2.7 THE CARIBBEAN AND AFRICAN COMMUNITY IN GM

Notably within GM as in other major urban cities within England, Black and Minority populations suffer worse health than other population groups. (see figure 2). Greater Manchester is rich in its diversity however, the majority of the 4% of the Caribbean and African Population live and work largely in the most deprived parts of the region. Black people hold less than 0.7% of senior roles across employment which includes those held within health and care agencies (see chart 4 - SOC2010, 2011).

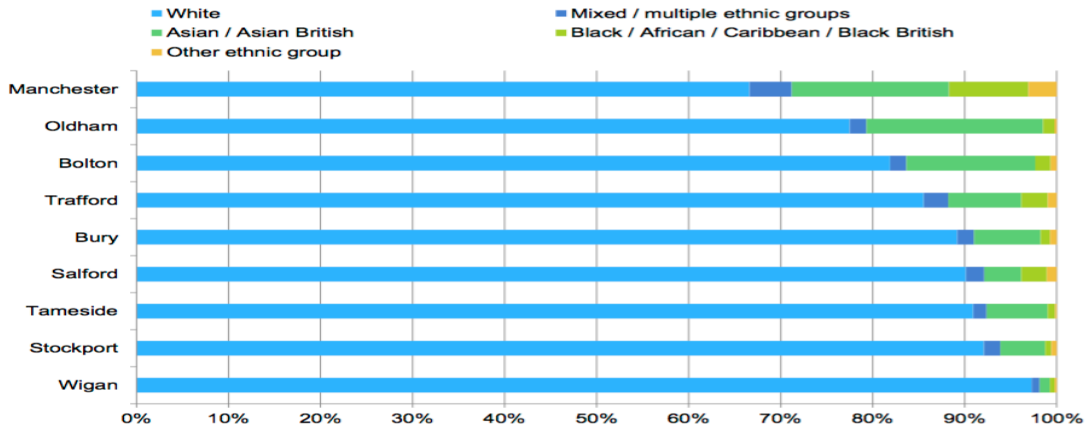


Figure 2: Greater Manchester cultural diversity

Chart 4: **MANAGERS, DIRECTORS & SENIOR OFFICIALS** in employment by Ethnic Group

Ethnic Group	UK OVERALL		NORTH WEST REGION	
	Managers, Directors and Senior Officials *(actual numbers)*	**% of total Managers, Directors and Senior Officials**	**Managers, Directors and Senior Officials in the North West of England** *(actual numbers)*	**% of total Managers, Directors and Senior Officials in the North West of England**
All	2,948,500	-	296,500	-
White	2,701,800	91.6	278,200	94.0
Mixed	17,400	0.5	2,300	0.7
Indian	70,900	2.4	3,100	1.0
Pakistani/Bangladeshi	44,400	1.5	7,500	2.5
Black	37,900	1.2	2,200	0.7
Other Ethnic Group	74,000	2.5	3,200	1.0
Total Ethnic Minority	**246,700**	**8.3**	18,300	6.0

Source: NOMIS ONS Annual Population Survey (APS) - Regions: Table T15 Employment by occupation (SOC2010) and ethnic group - Oct 2011 - Sep 2012
Notes: * means estimate and confidence interval not available since the group sample size is zero or disclosive (0-2). '-' means these figures are missing. ^ means estimate is less than 500

3. LITERATURE REVIEW

The systematic literature search was undertaken and included databases such as OvidSP, Medline, CINAHL, EMBASE and Google Scholar. Selected academic literature, scholarly articles, journal articles and books were hand searched. Boolean terms used OR, AND or NOT.

1.	Afro* African or Caribbean* African Caribbean or African AND Caribbean or Afro/Caribbean, NOT BME, NOT BAME
2.	Faith or AND Religion, or AND spirituality or AND Pentecostal or AND Beliefs or Faith Groups
3.	Engagement or AND involvement, partnership or collaboration, OR Community
4.	Prevention ill health promotion
5.	Knowledge or Health Literacy, Training or AND Workshop
6.	health or AND Health Inequalities
7.	Decision Making or Boards or Strategic AND or Leaders or Leadership Faith Leaders
8.	qualitative AND OR Focus groups or interviews OR AND Research

Table 1 – Search terms used for the literature review

All papers published between within the last 15 years were considered in the literature review. A literature review of health activity in the faith community especially that within the black church with literature drawn from the UK and the United States.

3.1 INTRODUCTION TO THE REVIEW

The past four decades have witnessed a wealth of studies on religion and the associated health benefits for African and Caribbean people. (Moreira-Almeida et al., 2006). However, certain questions remain. The project entailed a review of the literature pertaining to strategic health engagement and involvement of faith leaders within the Caribbean and African Community. Despite research on the benefits of faith and health, there is a paucity of evidence that relates to the development of faith leaders. There is a dearth of evidence of how to strategically respond to the health needs of their congregants

or those that seek their support in the community. To add, there is a limited body of evidence that highlight partnerships with BMC faith-based organizations to address health inequalities among congregants.

In order to highlight the truly innovative nature of the programme, literature that referenced a range of search terms were used (see table 1). This review highlighted that this piece of work was innovative as it pointed out that the pieces of research found do not fit the specific combined elements (faith, black, decision making, health literacy, engagement).

3.2 FAITH AND HEALTH IN THE BMC

The last census indicates that although there has been a decline in the number of citizens belonging to a religious group, the UK has seen extensive growth of some faith traditions (Office for National Statistics, 2011). Census data (ONS, 2011) informs us that Christianity is increasing amongst those born in countries outside of the UK.

However, and despite this, there exists a body of evidence which points to the role that religion, and spirituality can play in people's lives especially when in need of support and care. (Lawler-Row, 2009). In a study by Rodgers, (2013 pg 44), faith leaders reported the high expectations of pastors "...the people depend on you so much." In a sense that they will call you, they want you 24 hours a day, you are their counsellor, you are their lawyer, you are their doctor, you are their papa, you are their mother, you are everything to them because they say that whatever they need when they come by prayer they'll receive….."

3.3 SPIRITUALITY, AND HEALTH BELIEFS

Historically, Faith-Based Organisations (FBOs) have been a longstanding presence in the African Diaspora providing health and social support long before hospitals were developed. Pentecostalism is a form of Christianity in which believers emphasise a direct personal experience of God and the transfer of spiritual gifts such as speaking in tongues and divine healing. In Pentecostalism, the power of healing and miracles through prayer is a central cornerstone of the faith and congregants look to their leaders to be the giver of advice and guidance. Faith leaders are deemed to be instrumental in motivating others in church congregations to take more responsibility for their health. A poplar scripture reading states 'Is anyone among you sick? Let them call the elders of the church to pray over them and anoint them with oil in the name of the Lord. And the prayer offered in faith will make the sick person well; the Lord will raise them up. If they have sinned, they will be forgiven.' (James 5:14-15, New International Version).

A study on religion and coping (Taylor and Chatters, 2010) found that 90% of black people indicated the importance of spirituality as a protective and mediating factor in their life and 86% reported the importance of prayer when dealing with stressful events. The study also showed that Black people participated in church activities in far greater numbers than their white counterparts. (e.g., self-reported religiosity) religious activities (Taylor & Chatters, 2010).

3.4 THE BMC AND HEALTH ACTIVITY

In Caribbean and African communities, research supports that church attendance is an important religious activity that provides connectedness, support as well as for meeting their spiritual needs (Boyd-Franklin, 2006). A report published by the University of Roehampton (Being Built Together – A Story of New Black Majority Churches in the London Borough of Southwark, 2013), shows that Southwark has seen a significant rise in the number of post 1950s churches, particularly BMCs, many of which are Pentecostal with a largely Caribbean or African membership. The study found that an estimated 20,000 people gather to worship in around 240 different churches across Southwark each week (Rogers, 2013).

There is a growing amount of research particularly found within the African American church (Campbell, 2007, Newlin, 2012) and more recently in the UK (Mantovani (2015) to indicate the importance and effectiveness of health prevention interventions in faith-based organisations. Saunders et al. (2013), and Drake et al, 2010) undertook and evaluated a spiritually-based educational intervention within churches to raise prostate cancer screening and informed decision making among African American men. The findings reported that churches were successful spaces for educating African American men.

People of Caribbean and African descent are at high risk of developing mental ill health (Keating, 2007, Cabinet Office, 2017), High blood pressure, diabetes, stroke and heart disease are risk factors for dementia (Agyemang, 2003, Bhopal, 2007, Greencross, 2013). Knowledge of dementia and depression among African older people is limited and assumptions may be made by medical professionals about family care leading to lack of appropriate information and support. There is a body of published evidence around religion and mental wellbeing which points towards a positive association between religion and spirituality and better health and psychological wellbeing (Koenig, 2004; Pargament et al., 2004). A study by Dalencour (2017) adopted a qualitative approach of in-depth interviews to explore the knowledge and beliefs clergy members had about

depression. A number of themes emerged that identified the need for mental health education and training to enable them to support and respond to their congregants.

Evidence from largely African American churches have worked towards offering health promotion activities to increase health literacy (Lamb, 2014) such as screening for conditions such as high blood pressure, HIV and offering activities to combat loneliness and isolation in older people. African American churches strive to attend to the spiritual, mental, and physical needs of their members. A qualitative faith based organizational study by Mantovani (2015) using semi-structured and one-to-one interviews focused upon examining the relationship impact of developing the mental health knowledge base of 13 lay African Caribbean people. The co-produced pilot study with public sector and community organisations found that lay champions experienced barriers to change with the community of influence due to the stigma and taboo surrounding mental health. Despite the potential to prevent and promote better health such as mental health in the black community, existing government strategies such as “No Health without Mental Health do not partner with BMC to address mental wellbeing.

3.5 SUMMARY

Overall, the literature review recognises that there is some activity taking place within BMC, however, this health activity is at the operational level to address people’s holistic health and wellbeing. There was no evidence base for developing faith leaders to promote involvement, partner and exert influence at the strategic levels of health care systems.

4. METHODOLOGY AND METHODS

The literature review found no evidence of activities to enhance the health literacy of faith leaders in the BMC. Therefore, this project had a number of aims and objectives

4.1 AIM

To implement and evaluate the framework for a bespoke community leadership programme to improve health knowledge for strategic decision making within the context of the 5 year forward view (NHS, 2014).

4.1.1 Objectives:

1) Engage faith leaders and champions in a focus group consultation to develop the programme
2) Run the programme with attendance of faith leaders from black majority faith organisations
3) Evaluate whether the programme has improved health knowledge to enable participants to navigate the health system.

The project was conducted over a period of approximately 5 months, commencing in March 2018. The project took a participatory action research approach through which knowledge, solutions and recommendations would be generated by the participants and for the key stakeholder agencies. The project was evaluated over two 2.5-hour workshops.

4.2 METHODOLOGY

The research methodological approach project adopted a participatory action-based approach to develop a responsive evaluative methodology. This methodology is based upon reflection, data collection and action to influence the practices that can improve health inequities (Kolb 1984).

4.2.1 Methods

Designing appropriate methods was extremely important and were determined by the aims and objectives of the study. The methods utilised required a robust framework to ensure reliability and validity of the results and to demonstrate that they were appropriate to the evaluation questions.

A qualitative mixed-methods approach of focus groups and semi structured interviews were adopted for this study. Focus group interviews emphasize the importance of collecting in-depth individual perspectives in a group context (Kitzinger, 1994, Wilkinson 2004) and is closely linked to the growth of participatory research, (Morgan, 1997). As well an enable the views of others to trigger responses from others, (Gillham, 2005) focus groups provide the group with more control over the discussion whilst the researcher only serves to mediate the session. As such, this approach was deemed most appropriate given the emphasis on exploring the collective perspectives of the faith community. A semi-structured focus group guide (See appendix G) was developed based on prior consultative formative work.

Semi structured interviews were conducted over the phone to collect the data from the stakeholder leaders. The interviews were undertaken with the speakers following the CLP workshop. This was carried out to explore their expectations from the programme, delivery of their presentation, engagement of the participants and to identify any aspects that would enhance the health literacy of faith leaders to influence strategic decision making. Both sets of data was used to inform the evaluation of the CLP and to identify the next steps for improved service delivery.

A series of focus group and semi-structured interview questions were provided to guide the participants (see Appendix B). Subsequent responses led to further questions, thus enabling the individual participant perspectives to emerge.

4.2.2 Setting for the Project

The study took place in Manchester and was conducted in a conference setting for day one. This allowed participants the opportunity to build relationships with each other away from the community setting and decreased the possibility of distraction from daily life and other obligations. The two evaluation days took place within a faith-based community setting during the evening.

4.2.3 Recruitment of Participants

A purposive sample approach was used, and an invitation went out to ministers and faith leaders (see appendix A) based on respondents' unique characteristics using the pre-existing Caribbean and African Health Network database. The sample was recruited based on their leadership roles in predominantly Black Majority churches across Greater Manchester. The programme's organizers from Caribbean and African communities facilitated the recruitment process; they co-designed the information material explaining the purpose of the study. (see flyer appendix C)

The criteria for participation included:

- Caribbean and African descent
- 18 years and above
- Faith Leaders across church departments

To ensure as much diversity as possible in focus group composition, each focus group comprised of individuals from either majority Caribbean or majority African faith organisations. The diversity also consisted of faith leads that adopted different doctrines such as Pentecostal, Seventh Day Adventist.

Statutory Strategic Sector leads were selected to provide a presentation based upon the case studies (See appendix E for case study template and example) faith leaders were asked to provide prior to the workshop. (See appendix D for training programme)

4.3 DATA COLLECTION

The focus group data (See appendix F for Focus group questions) was collected directly from participants and facilitated by the research team using a topic guide. This broad guide was developed to gain an in-depth understanding of faith leaders experiences of the CLP workshop and to make recommendations for improved involvement and engagement in health service design and delivery. The data from the focus group was collected over three phases using flipcharts and notetaking from our research assistant. The semi-structured interviews were audio recorded and transcribed verbatim. (see Appendix G for semi structured interview schedule). The data sought to identify issues raised from the programme and how it actually worked in achieving the aim of the study.

4.4 DATA ANALYSIS

A thematic analysis was undertaken on the qualitative data. Two research assistants undertook this analysis independently and a consensus of the key themes emerging from the data was achieved through discussion. The data from the in-depth semi -structured interviews were analysed in the same way as the qualitative data from the focus groups.

The focus group data was collected on flip chart paper and through note taking from a research assistant, then transcribed and analysed using thematic analysis. Thematic analysis is a method for identifying, analysing, and reporting themes that emerge within the data (Braun and Clarke, 2006). Due to the lack of research in this area, it was important to generate a real understanding of the data and generate the important and reoccurring themes.

The audio- recorded data was transcribed verbatim and the transcripts were checked by the research assistant to ensure the information collected was accurate prior to themes being generated.

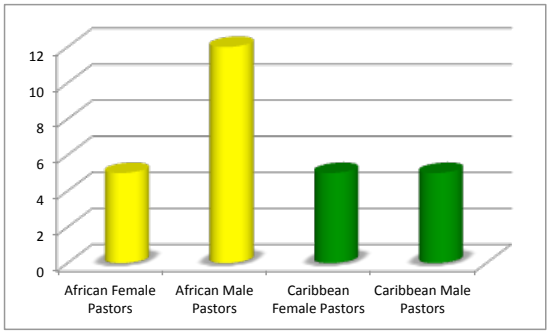
4.5 ETHICAL CONSIDERATIONS

The project sought permission from Manchester Metropolitan University research Department. Prior to interviews and focus group, participants were informed of the details of the study and provided with the participant information sheet (Appendix B) and the consent form to sign. The information sheet included details of the study so that participants could make an informed decision about completing the programme. Participants were unidentifiable throughout the report. Informed consent was revisited verbally prior to each focus group session and interview.

5. FINDINGS

A total of 27 male and female faith leaders attended the CLP workshop and identified as being of Caribbean or African Heritage (see table 2). Of all of the leaders that attended the session, 3 of these had attended health engagement events that discussed co-production and co-design of health services.

Two focus group sessions were conducted 6 weeks apart with the individuals that attended the CLP. However, not all attendees were able to take part in the focus group sessions. This meant that feedback was collected individually from some participants so that the data between the two meetings were complete. Lower attendance points were due to structural issues within community. As such, there was the need for alternative engagement plans to contact them with telephone discussions and questions asked at the focus group sent via email for them to answer within a particular timeframe. Community relationship building enabled me to adopt this alternative approach to collect the data individually. All speakers that presented at the CLP workshop took part in semi-structured interviews (see interview questions – (Appendix G)



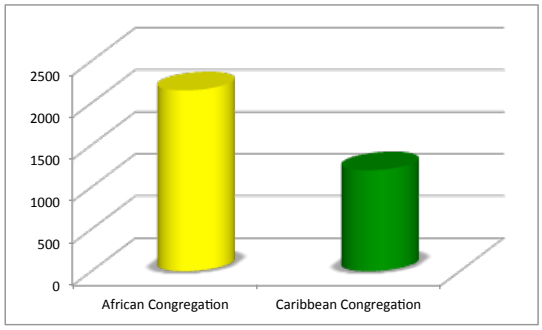


Table 2. Demographic Information and Religious Affiliation of Focus Group Participants

Four key themes emerged from the data and were grouped into categories.

EMERGENT THEMES IN FOUR CATEGORIES - THEMATIC ANALYSIS OF FAITH LEADERS PERSPECTIVES

1) Empowering for engagement in health systems and delivery
2) Resources - Partnerships/collaborations/engagement
3) Faith, Spirituality in health and healing
4) Engaging with Decision Makers at Strategic Levels

We elaborate and illustrate those themes here using direct quotes

5.1 EMPOWERING FOR ENGAGEMENT IN HEALTH SYSTEMS AND DELIVERY

Participants frequently spoke about the limited information regarding pathways to health information. These included tailored information relevant to their communities around about common health conditions. Signposting to services - need early detection, address cultural barriers, and low level of education. Many faith leaders were unsure how to recognise conditions especially mental illness among their congregants and did not know how to support them.

"There is a need for those trained within the health and care sector such as doctors and nurses to share information so that we can link the messages to scripture. Without the knowledge we cannot help our people". (Participant 1, African Male pastor)

One of the participants expressed that they wanted to be confident in how they could be trained to recognise mental health illness and deliver their own tailored services rather than signpost to statutory services because of the negative experiences of the community.

"I found it quite interesting that one of the speakers shared with us about IAPT services and very few of us knew what it was" ….. For me, this demonstrated poor engagement and information sharing with our community especially when our people suffer high levels of mental health (Participant 2, Caribbean Male Pastor)

There was a common understanding that some of their congregants preferred to receive services from a faith-based organization they could associate with. Trust, identity, shared beliefs and values were also highlighted by leaders as a factor that impacts upon the engagement of congregants. For some people, faith is an important part of their identity and they want the services that are offered to them to acknowledge that.

"It is often the case that the information we read is not relevant to our community and therefore it is more likely that the message is totally ignored. We need services to acknowledge our faith as well as our cultural needs when delivering services. It is right that we get involved and influence how services are designed and developed." (Participant 18, African Female Youth Leader)

"I am not trained as a health professional; however, I try to get the information to help those that approach me for support which is quite daunting for me as their faith leader. Congregants often approach me because they believe that I can help". (Participant 14, Caribbean Female Pastor)

5.2 TRANSPARENT RESOURCE ALLOCATION

Overall, Faith leaders shared that they did not encounter offer to resource faith-based health activities or training within their church. Many of the participants except three did not know where they could seek resources and support to carry out health improvement and health prevention work. The result of this lack of knowledge resulted in no activity within many of the churches.

"Despite the fact that I have a large congregation and live in an area of deprivation, I have never been approached by a statutory organization to access my church for health improvement work". (Participant 7, African Female Pastor*)*

"As someone who is familiar with the health care landscape in Greater Manchester……..there is very limited effort from the statutory sector (especially those in health prevention) to engage with the black majority churches" (Participant 11, African Male Pastor)

In our church we undertake some health prevention work but only on a small scale, resources are a big problem but we know our congregants need the health information (Participant 7 African female Pastor)

A recurring theme with faith leaders is that links with statutory and voluntary/community partners generally take place when there is someone in the faith organisation with the understanding, interest and capacity to get involved. These were stated as health professional such as nurses, doctors and allied health professional. However as evidenced in the literature there is limited representation of Caribbean and African health professionals at senior levels, (Klein, 2014).

We have a health ministry run by health professionals as one of the departments in our church, but it is not resourced or initiated by public sector agencies but by the congregants themselves who are often socio-economically challenge. We need proper investment to sustain health services that our people want to use and our health professionals should be influencing and involved in public sector decisions. (Participant 2, Caribbean Male Pastor).

"I never really thought of it until the CLP programme however, capacity building of faith leaders is important in the areas of – advocacy, building partnership and conducting risk assessment in relations to health issues of the congregants". (Participant 5, Caribbean Male Pastor).

5.3 FAITH, SPIRITUALITY, AND HEALING AND THE HEALTH SYSTEMS

A number of faith leaders expressed concern over the lack of awareness articulated from stakeholders with regard to the importance of the faith, health and healing

"I was particularly gripped by the presentation from the minister and mental health worker relating to the place of faith in mental health, it brought out the importance and significance of faith in health care and recovery. …. This information was of most interest to me". (Participant 10, African Female Church Leader)

"One of the presentations from a senior decision maker was quite concerning as they were not aware of the importance of faith in health of our community. This is where we need to be around the table sharing the important needs of our community when services are being designed". (Participant 5, Caribbean Male Pastor)

One of the leaders spoke about the lack of awareness from hospital staff when praying for patients. As supported by the analysis of the 'Picker Inpatients surveys' between 2007 and 2009, findings that, on average, 22% of patients identified belief as 'an issue' while in hospital, 17.7% of patients wished to practise their religion, 2.1% reported that their beliefs were not fully respected and 2.9% were not able to practise their religion as they had wished, (Clayton, 2010).

"I remember visiting an unwell member of our church in hospital with a few of the other church members and being told we could not pray with our church member. It is not okay to be told that we cannot pray aloud because we are disturbing other patients". There should be the resources to accommodate the spiritual needs of our members when they are sick in hospital" (Participant 9, African Male Pastor*)*

One of the participants spoke about the role of faith leaders in healing and prayer and the need for a mutual understanding from public sector agencies within the BMC with regards to health beliefs

… "health of our congregants are important, for me there however needs to be some separation of church and state: Churches may be truly interested in promoting and engaging in health activity but we need to be mindful that the state does not disrespect or undervalue that our mission is to save souls" (Participant 6, African Male Pastor)

5.4 ENGAGEMENT AT STRATEGIC LEVELS

Some of the leaders described the challenge that Caribbean and African faith-based organisations have when wishing to engage in the wider health and care system. Some pastors spoke of the financial constraints their churches were under, and the cost of premises as many of these were rented for large sums of money. This meant that a number of the faith leaders had to attend to full or part time jobs as the tithes and offerings (where congregants give 10% of their earnings towards the upkeep of the church) given by congregants could not sustain pastors financially in their ministry.

"For me, it is all about capacity and appropriate resources to engage in a meaningful way. I do not want to pay lip service by sitting around the table and then nothing happens to change the poor health experiences of my congregants". (Participant 8, African Male Pastor)

Overall, faith leaders evaluated that the CLP was a real opportunity for the strategic sector leaders to learn about the black community, the activities taking place within the faith organisations and why faith impacted many health decisions in the black community.

"The day provided a good access to decision makers and revealed how little was understood about how faith and health impacts a large section of the black community". Participant 3, African Female church department Leader

5.5 THEMATIC ANALYSIS OF STAKEHOLDER PERSPECTIVES

Two themes were apparent from the semi-structured interviews with the stakeholders

5.5.1 Lack of understanding of the importance of faith and faith leadership and health in decision making of congregants

Some of the speakers recognized that there was a lack of awareness of the importance attributed to faith and health care in the black community.

"I did not realise that faith was so important in health care decision, I don't really come across many Caribbean or African people in my area of practice" (Participant 1, GP Commissioner)

It is really useful to understand the needs of different people when providing services, I now realise the emphasis placed on prayer and healing in this community and the need to adjust the way my service is run (Participant 4, Partnership Lead)

5.5.2 The need to engage and partner with Black Faith leaders

"Taking part in this workshop has made me realise more acutely how Faith Leaders are ideal partners with health and care agencies due to the access, trust and influence they have with large sections of the community" (Participant 3, Strategic Sector Lead, Local Authority)

As a Director for my department, I would welcome the opportunity to work with Faith Leaders to learn from them and to improve the health of this community" (Participant 2, Acute Hospital Clinical Director).

"The knowledge I have received from this workshop provides me as a strategic lead with the evidence to intervene and provide forums where faith leads can influence and enable change in the health services that are being delivered and where they are delivered and who they are delivered by" (Participant 3, Strategic Sector Lead, Local Authority

It is vital that we work collaboratively with this community especially faith leaders given their influence and understanding of their own congregants (Participant 1 GP Commissioner).

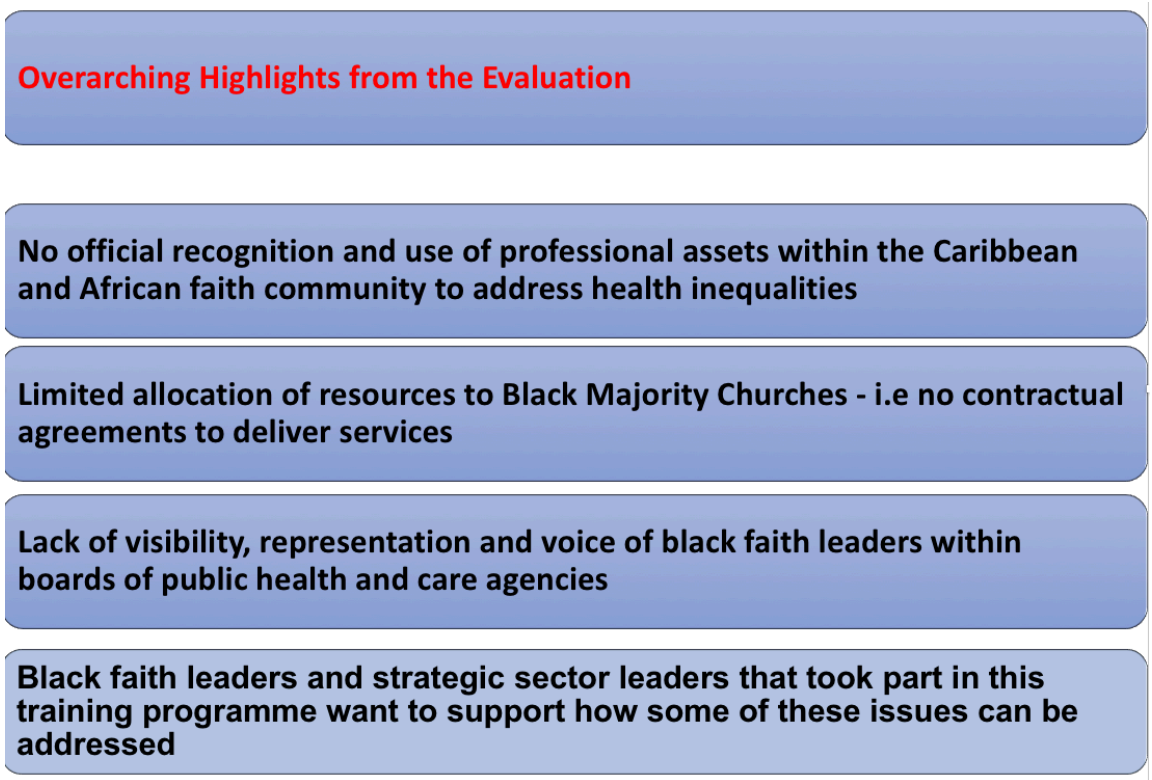
6. DISCUSSION

A key element within the 5YFV (2015) is focused upon how we prevent ill-health through empowering patients, it also emphases the importance of collaborative and partnership working with communities to achieve the NHS core objectives and sustainability.

As highlighted in the literature review, the BMC is a successful space where black people can gain access to health information (Saunders et al (2013), Drake et al, 2010). However, despite this, the findings from the evaluation of the Community Leadership Programme for Caribbean and African Faith Leaders in Greater Manchester illustrates that although many faith leaders offer health and wellbeing support in varying levels, they do not feel that they are equipped with the necessary health literacy to support and signpost their congregants. Overall, faith leaders do not feel that they can act as advocates for them in the wider health care decision-making arena. This is due to lack of involvement and awareness of the health care landscape and how the health care system in GM functions to enable access to appropriate services. It was important to ascertain through this study what the needs of faith leaders were to enable engagement at decision making levels to inform and improve health outcomes. In this study, faith leaders expressed a desire to get involved to influence and inform health decisions however they also recognized the resource implication of this involvement.

What has transpired from this study is that there is:

1) Limited recognition of the value that faith leaders can offer to the health system to engage the Caribbean and African Faith Community for improved health outcomes.
2) No sustainable investment in the infrastructure of the BMC and that Greater Manchester statutory sector stakeholders are not engaging with the BMC at the strategic or operational level
3) A desire from faith leaders as gatekeepers to engage with senior decision makers to co-design and co-produce religiously and culturally appropriate services so that they impact health improvement in the black community
4) Both Faith leaders and strategic sector leaders want to work together to look at how some of the issues raised can be addressed.



6.1 VALUE OF THE ASSETS WITHIN THE CARIBBEAN AND AFRICAN FAITH COMMUNITY

Faith leaders recognize that they are the first point of contact in a number of cases for their congregants who are in need of spiritual succour as well support with health, care and wellbeing support (Rogers, 2013) The health disparities across a number of health conditions in the Caribbean and African community has been explored extensively in the literature yet there is limited level of recognition of the role that BMC can play here in Greater Manchester. In light of GM devolution, our commissioners need to be aware of the potential for partnership and collaborative working with BMC. Despite the significant numbers of church attendees from this community and the support faith leaders provide to their congregants sometimes through their health ministries, there is no resource recognition of that within statutory service commissioners. In this study faith leaders recognized the assets in the health professionals within their church who are able to offer health care support. This study has highlighted that although a significant number of black health professionals work across the NHS and Care sector, very few are operating at senior levels to impact change.

6.2 THE INVESTMENT IN THE INFRASTRUCTURE OF THE BLACK MAJORITY CHURCH

Overall, Black Caribbean and African community organisations do not have the infrastructure to develop sustainable health care services. All but three of the participants talked about their lack of awareness of how the system works and how they can get resource support to address health in their community. Participants from this study provided no evidence of CCG or Statutory sector engagement or involvement with BMC and no efforts to increase health capital.

Although strategic involvement of faith leaders in health care service design is seen as extracurricular by some faith leaders, they recognise the importance of the health of their congregants. Faith leaders within the BMC are principally well-respected organisations. They are an under used resource that can bring about change in the health service delivery and practices. This can be delivered through information sharing that can improve health capital and subsequently aid economic benefit. There is a failure on the part of CCG's and other statutory providers to develop an effective infrastructure for effective partnerships with BMC to address health disparities in the Caribbean and African Community in Greater Manchester.

6.3 ENGAGEMENT OF FAITH LEADERS AND STRATEGIC SECTOR LEADERS

There is a wealth of evidence in the literature that highlights the lack of representation of black people at senior decision-making levels (Klein, 2014). As highlighted in this study, it means that black people do not have a voice and their needs are not understood or catered for. Strategic sector leads were keen to develop a platform whereby faith leaders could be involved in the development of appropriate services that would help to address health inequalities. Strategic leaders saw this as an opportunity to learn from faith leaders to influence their own practices.

6.4 LIMITATIONS TO THE PROJECT

There were a number of limitations associated with the project. It was a small exploratory study with 27 faith leaders and a small sample of strategic sector leads and may not be generalizable beyond the participants of this study. However, the study was not intended to be representative of all Caribbean and African Faith Leaders. The aim here was to gain a deeper understanding of the health literacy needs associated with involvement and

engagement of faith leaders so that they could influence decision making on behalf of their congregants.

Given the nature of the roles that faith leaders participate within, the focus group evaluations sessions did not yield the attendance from all participants. This resulted in collecting data on a one to one basis. This may have impacted the results as these participants did not gain the same interactions with other participants.

7.CONCLUSION

This evaluation report raises important questions for policy and practice not only at the local level but also at the wider national level. We need to look again in more depth at the policy and practice experience, and the wider societal changes that could give rise to addressing health inequalities in and across communities. For better partnership to be achieved and for health systems to be strengthened by the alignment of faith-based health-providers improved information and engagement is needed at all levels. There is a lack of black representation in decision making within the NHS, and across services.

The voluntary and community sector has attempted to address gaps in provision by delivering tailored health and wellbeing interventions however there is a lack of economic capital and investment from the public sector.

Our findings suggest that to address health inequalities within the BMC requires a partnership approach with statutory or public-sector partners at all levels of the system. New models of provision should be implemented to provide culturally, spiritually appropriate and responsive health care information and services that address the needs of a community impacted by poor health. From the review of the literature, it is clear that there is a wealth of health and wellbeing activities taking place in BMC especially in African American places of worship. Judging by the range of health and care services offered by BMC, the findings reinforce the claim that faith communities are closer to the local community and access people that other agencies deem “hard to reach”. Therefore, in a region of significant health inequality and poor health outcomes within the Caribbean and African Community, Greater Manchester has an opportunity to utilize the assets from within the BMC.

This project has highlighted that further action and research needs to be undertaken to put into place a programme that can equip faith leaders to engage at senior levels of the health care system.

8. RECOMMENDATIONS

- There should be a transparent process led from the top of organisations to enable faith leaders from the BMC to access and represent their community on decision-making boards. This will require BMC to identify the assets (such as health care professionals) within their churches so that the relationship between public sector agencies and Faith-based organisations can be fostered.

- There must be fairness under the Equality Act (2010) from those procuring and commissioning services to resource the BMC to engage, participate and deliver health initiatives to improve health outcomes. This should include a system where the community can hold commissioners to account for disparity in resource allocation.

- It is important to deliver a tailored programme of education and training to equip faith leaders with the knowledge needed to support and signpost congregants to appropriate services that enable them to improve health

- There must be an agreed stakeholder practice and protocol guidance that enables faith leaders to deliver religious healing activities within safe spaces of secondary care organisations.

8.1 IMPACT ON POLICY, PRACTICE AND DISSEMINATION – CALL TO ACTION

My intention is that this report and the information contained within it, stimulates a discussion with senior decision makers here in Greater Manchester and NHS England. Visionary and committed leadership is required from the top in order to achieve sustainable transformational change and provide equitable health care. The intention is to move beyond the pilot to deliver an empowering CLP that can be relevant to a wider set of faith communities. It should end with action planning that can be written up and published to hold powerbrokers to account.

9. REFERENCES

Adedibu, B. (2012) 'Coat of Many Colours: The Origin, Growth, Distinctiveness and Contributions of Black Majority Churches to British Christianity', Gloucester: The Choir Press.

Ahmad, W. I. U. and Bradby, H. (2007) 'Locating ethnicity and health: exploring concepts and contexts', Sociology of Health & Illness, 29: 795-810.

Agyemang, C., Kunst, A, Bhopal, R et al. (2011) Diabetes Prevalence in Populations of South Asian Indian and African Origins a Comparison of England and The Netherlands. Epidemiology, 2011; 22: 563–567.

Agyemang, C and Bhopal, R. (2003) Is the blood pressure of people from African origin adults in the UK higher or lower than that in European origin white people? A review of cross-sectional data. J Hum Hypertens 17, 523–534

Aldred, J. (2007) 'Black Churches contributing to cohesion or polarising Christians and other faith groups?'. Churches Together in England [Online]. [Accessed 6th August 2018] http://www.cte.org.uk/Articles/82343/Churches_Together_in/Features_Reviews/Features/Black_ Churches.aspx

Ayinde, H, Gillum, R. (2014) Cardiovascular disease mortality in Sub-Saharan Africa and the Caribbean. Ethnicity & Disease, 24: 495–501.

Bécares, L., Stafford, M., Laurence, J and Nazroo, J. (2011) Composition, concentration, and deprivation. exploring their association with social cohesion among different ethnic groups in the UK, Urban Stud., 48 (2011), pp. 2771-278

Bécares L. (2013) The Dynamics of Diversity: Evidence from the 2011 CENSUS. Centre on Dynamics of Ethnicity (CoDE). Manchester, UK: The University of Manchester

Bhopal, R. (2007) Ethnicity, Race, and Health in Multicultural Societies; Foundations for Better Epidemiology, Public Health, and Health Care, Oxford University Press

Bhopal, R. (2009) Chronic diseases in Europe's migrant and ethnic minorities: challenges, solutions and a vision. Eur J Public Health; 19:140-143.

Bowe, A. (2015) Exploring social and psycho-social factors that might help explain the Afro-Caribbean boy underachievement in England. International Journal of Educational Development; 42: 73–84.

Boyd-Franklin, N. (2006). Black families in therapy: Understanding the African American experience. Guilford Press

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. Qualitative Research in Psychology, 2006; 3: 77–101

Campbell, M., Hudson, M., Resnicow, K., Blakeney, N., Paxton, A., and Baskin, M. (2007) Church-based health promotion interventions: Evidence and lessons learned. Annual Rev Public Health 2007; 28:213–34

Clarke, G., Jennings, M., Shaw, T. (Eds.) (2008) Development, Civil Society and Faith-Based Organizations Bridging the Sacred and the Secular; Palgrave Macmillan

Clayton, A. (2010) Religious Need in the NHS in England. The Contribution of Picker Inpatient Surveys. Unpublished Report commissioned by the Diocese of Ripon and Leeds. [Online] (accessed 3rd August 2018)

https://researchgate.net/publications.260025691_Religious_need_in_the_NHS_in_England_The_Contribution_of_Picker_Inpatient_Surveys

Department of Communities and Local Government (2015). The Indices of Deprivation 2015. Research Report.

Dalencour M, et al. (2017) “The Role of Faith-Based Organizations in the Depression Care of African Americans and Hispanics in Los Angeles. Psychiatric Services. 2017. 68(4):368-374.

Dewalt D., Berkman, N., Sheridan, S, et al. (2014) Literacy and health outcomes: a systematic review of the literature. Journal of General Internal Medicine ‘19(12):1228-39

Drake, B. F., Shelton, R., Gilligan, T., and Allen, J. (2010). A church-based intervention to promote informed decision making for prostate cancer screening among African American men. Journal of the National Medical Association, 102(3), 164-171.

Edge, D. (2013) ‘Why are thou cast down, o my soul?’ Exploring intersections of ethnicity, gender, depression, spirituality and implications for Black British Caribbean women's mental health. Critical Public Health, 23: 39–48. (Special Edition on Black and Minority Ethnic Women's Health).

Equality and Human Rights Commission. (2011) Public Sector Equality Duty, [Online] [Accessed 20 June 2018] http://www.equalityhumanrights.com/private-and-public-sector-guidance/public-sector- providers/introducing-the-duty

Gillham, B. (2005) Research Interviewing – The Range of Techniques, Maidenhead, Open University Press, McGraw-Hill Education

Greater Manchester Combined Authority. (2015) NHS in Greater Manchester. Taking Charge of our Health and Social Care in Greater Manchester.

Greengross, S. (2013) All-Party Parliamentary Group on Dementia Dementia does not discriminate: the experiences of black, Asian and minority ethnic communities, London

Health and Social Care Act 2012, c.7. (Accessed: 8 July 2018) http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted

Kajumba, D. (2013) Statistics on BAME Priests in Senior Posts are 'Shocking', Church Times

Karlsen, S. (2007). Ethnic inequalities in health: the impact of racism. Better Health Briefing 3. London, England: Race Equality Foundation. Retrieved from http://www.better-health.org.uk/briefings/ethnic -inequalities-health-impact-racism

Keating, F. (2007). African and African Caribbean men and mental health. Better Health Briefing Paper 5. Retrieved from http://www.raceeequalityfoundation. org.uk/

Kitzinger, J. (1994) The methodology of focus groups: the importance of interaction between research participants. Sociol Health Illn.16:103–121. doi: 10.1111/1467-9566.ep11347023

Kline, R. (2013) Discrimination by appointment: how black and minority ethnic applicants are disadvantaged in NHS recruitment. London: Public World [Online] [Accessed on 5th May 2018] http://www.publicworld.org/files/Discrimination_by_appointment.pdf

Kline, R. (2014) The "snowy white peaks" of the NHS: a survey of discrimination in governance and leadership and the potential impact on patient care in London and England. [Online][Accessed on 12 June 2018] http://www.mdx.ac.uk/__data/assets/pdf_file/0012/59799/The-snowy-white-peaks-of-the-NHS.pdf.pdf

Koenig, L, Titus, P. (2004) Religion, spirituality and health in medically ill hospitalized older patients. J Am Geriatr Soc, 52554- 562

Kolb, D. (1984) Experiential learning. Englewood Cliffs, NJ: Prentice Hall

Krueger, R. and Casey, M. (2009) Focus Groups: A practical guide for applied research. 4th ed., Los Angeles: Sage Publications

Lamb ,P. and Berry, J. (2014) Health Literacy – the agenda we cannot afford to ignore: Community Health & Learning Foundation

Lane, D., Beevers, D. and Lip, G. (2002) Ethnic differences in blood pressure and the prevalence of hypertension in England. J Hum Hypertens. 16(4):267–27

Lawler-Row, K. A., and Elliott, J. (2009). The role of religious activity and spirituality in the health and well-being of older adults. Journal of Health Psychology, 14, 43-5

Legislation.gov.uk. (2010). Equality Act 2010. [online] [Accessed 11 July. 2018] http://www.legislation.gov.uk/ukpga/2010/15/contents

LGA (2014) What is the role of Voluntary, Community and Social Enterprise (VCSE) organisations in care and support planning? National Voices [online] [Accessed 18 July. 2018]
http://www.nationalvoices.org.uk/sites/default/files/public/publications/what_is_the_role_of_vcse_organisations_in_care_and_support_planning.pdf

Lip, G., Barnett A., Bradbury, A. et al. (2007) Ethnicity and cardiovascular disease prevention in the United Kingdom: a practical approach to management. J Hum Hypertens. 21(3):183–211

Mantovani, N., Pizzolati, M., Gillard, S. (2014) Using my knowledge to support people: a qualitative study of an early intervention adopting community well-being champions to improve the mental health and well-being of African and African Caribbean communities. Monograph. London: St. George's University of London

Mantovani, N., Pizzolati, M. and Gillard, S. (2015) Engaging communities to improve mental health in African and African Caribbean groups: a qualitative study evaluating the role of community well-being champions. Health and Social Care in the Community

Moreira-Almeida, A. and Koenig, H. (2006). Retaining the meaning of the words religiousness and spirituality: a commentary on the WHOQOL SRPB group's ''A cross-cultural study of spirituality, religion, and personal beliefs as components of quality of life'' Social Science & Medicine 63 (4), 843–845

Morgan, C., Dazzan, P., Morgan, K. et al. (2006) AESOP study group. First episode psychosis and ethnicity: initial findings from the AESOP study. World Psychiatry, 5: 40–46

Morgan, D. (1997). Focus groups as qualitative research (2nd ed.). Thousand Oaks, CA: Sage.

Mowat, H. (2008) "The potential for efficacy of healthcare chaplaincy and spiritual care provision in the NHS (UK): A scoping review of recent research" Commissioned by NHS (UK) Yorkshire and the Humber

Newlin, K., Dyess, S., Allard, E., Chase, S., & Melkus, G. (2012). A methodological review of faith-based health promotion literature: advancing the science to expand delivery of diabetes education to Black Americans. Journal of religion and health, 51(4), 1075-1097.

NHS England (2014a) NHS Five Year Forward View. NHS England.

Office for National Statistics. (2013g), 'Regional Statistics: 2011 Census London Data Tables - Ethnic Group (QS211EW)'. [online] [Accessed 11 October. 2017] http://www.ons.gov.uk/ons/regional- statistics/region.html?region=London#tab-data-tables

NHS England. Next Steps on the Five Year Forward View. (2017) NHS England; [online] [Accessed 11 March. 2018] https://www.england.nhs.uk/wp-content/uploads/2017/03/NEXT-STEPS-ON-THE-NHS-FIVE-YEAR- FORWARD-VIEW.pdf

Office of National Statistics. (2011) Census: Key Statistics for local authorities in England and Wales. Ethnic group, local authorities in England and Wales. London: ONS, 2011.

Office of Public Sector Information. (1990). National Health Service and Community Care Act 1990 (c. 19). London, HMSO

Pargament, K. Koenig, H., Tarakeshwar, N. and Hahn, J (2004) "Religious coping methods as predictors of psychological, physical and spiritual outcomes among medically ill elderlypatients: a two-year longitudinal study, "Journal of Health Psychology, vol. 9, no. 6, pp. 713–730

Polletta, F. (2014) 'Participatory Democracy's Moment', Journal of International Affairs

Public Health England. (2015), A guide to community centred approaches for health and wellbeing, page 4 [online] [Accessed 9 July. 2018] www.gov.uk/government/uploads/system/uploads/attachment_data/file/417515/A_guide_to_community- centred_approaches_for_health_and_wellbeing__full_report_.pdf

Race Disparity Audit. (2017) - Summary Findings from the Ethnicity Facts and Figures Website, Cabinet Office, [online] [Accessed 11 August. 2018]

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/650723/RDAweb. pdf

Raleigh, V. (1997) Diabetes and hypertension in Britain's ethnic minorities: implications for the future of renal services. BMJ. 314(7075): 209

Rogers, A. (2013) Being Built Together, A Story of New Black Majority Churches in the London Borough of Southwark [Online]. [online] [Accessed 11 March. 2018]https://www.roehampton.ac.uk/globalassets/documents/humanities/being20built20togethersb203-7-13.pdf

Saunders, D., Schulz, E., Whitehead, T., Holt, C., Atkinson, N., Le, D. and Naslund, M. (2013). Development of the men's prostate awareness church training: Church-based workshops for African American men. Family & Community Health, 36(3), 224-235

Schneider, E., Zaslavsky, A and Milstein, A. (2005) Quality of care in for-profit and not-for-profit health plans enrolling Medicare beneficiaries. Am J Med 118:1392-400

Selman, L., Harding, R., Speck, P., Robinson, V., Aguma, A .and Rhys A et al. (2010) Spiritual care recommendations for people from Black and minority ethnic (BME) groups receiving palliative care in the UK. London Cicely Saunders Institute, Dep Palliate Care PaR

Swift, C. (2014) "Hospital chaplaincy in the twenty-first century: The crisis of spiritual care on the NHS". Ashgate Publishing, 2nd Edition,

Szczepura, A. (2005) 'Access to healthcare for ethnic minority populations.' Postgraduate Medical Journal, 81(953) pp.141-147.

Taylor. R., Chatters. L. and Jackson J. (2007) Religious and spiritual involvement among older African Americans, Caribbean Blacks and non-Hispanic Whites: Findings from the

National Survey of American Life. The Journals of Gerontology: Social Sciences. 2007;62: S238–S2

Taylor, R., Chatters, L., Mattis, J. and Joe, S. (2010) Religious involvement among Caribbean blacks in the United States. Review of Religious Research. 52:125–145

The Marmot Review Team. (2010) Fair Society. Healthy Lives: Strategic review of health inequalities in England post- 2010. London: Marmot Review Team

Tomlinson, J., Muzio, D., Sommerlad, H., Webley, L. and Duff, L. (2013) Structure, agency and career strategies of white women and black and minority ethnic individuals in the legal profession. Hum Relations. 66(2): 245-269

Van der Heide, I., Wang, J and Droomers, M, et al. (2013) The relationship between health, education, and health literacy: results from the Dutch Adult Literacy and Life Skills Survey. Journal of Health Communication 18 Suppl 1:172-84

Walshe, K., Coleman, A., McDonald, R., Lorne. and Munford, L. (2016) Health and social care devolution: The Greater Manchester experiment. BMJ. 22;352: i1495. [online] [Accessed 9 July. 2018] www.bmj.com/content/352/bmj.i1495

Wilkinson, S. (2004). Focus groups: A feminist method. In S.n. Hesse-Biber & M.L. Yaiser (eds.), Feminist perspectives on social research (pp. 271–295).New York: Oxford university Press

World Health Organisation Regional Office for Europe. (2013) Health literacy: The solid facts

10. APPENDICES

Appendix A – CLP Participation Letter

Participation Letter Dear Faith Leader _____:

My name is Faye Bruce, a Mary Seacole Awardee based at Manchester Metropolitan University. I am conducting a study to explore the health literacy of Caribbean and African of faith leaders. The study will be used to ascertain whether a Community Leadership Progamme could facilitate an improvement in health for the black community through engaging with Public sector senior leaders across the health and care sector. I will use a participatory approach to evaluate whether this programme has achieved in aims and to use recommendations to determine next steps concerning faith leaders decision-making processes

You are invited to participate in this study. You were selected as a participant because of your position as senior faith leader or pastor in your church.

Your participation will involve, identifying a cased study congregant that you can submit to me so that they can be used to facilitate learning and discussion with public sector leaders on the day. It will involve one full day's attendance at a one-day workshop and two half day follow up evaluation sessions with the researcher

If you are interested in participating in the study or have any questions you may contact me f.bruce@mmu.ac.uk

Thank you very much.

Sincerely,

Faye Bruce

Appendix B – CLP Participant Information Sheet

Participant Information Sheet

Date: 11/ 03 /2018

A qualitative study to identify the health literacy needs of Caribbean and African Faith Leaders to enable engagement in strategic health decision making on behalf of their congregants

This information sheet will:

- *Tell you what the study is about.*
- *Give you more detailed information about what will happen if you take part.*

Invitation

Thank you for reading this information sheet.

Before you make your decision whether to be involved or not, please read the information below about the study and why it is being undertaken. It is important to read this sheet carefully so that you are fully aware of what is required. Please contact the researcher Faye if you require any further clarification using the contact details on page

Purpose of the study

The study aims to explore the health literacy needs of Caribbean and African Faith leaders to enable engagement in strategic decision making about health service provision on behalf of their congregants

In order to obtain the data required, we will ask faith leaders from across the faith traditions to attend a community leadership workshop and evaluate the workshop over two focus group sessions. We will also ask strategic leads from across the health and

care sector to deliver a strategic presentation of their service provision and take part in a semi structured interview.

Why have I been invited?

You have been invited because you are a faith leader and will have leadership requirements amongst the congregants within your faith organisation

Do I have to take part?

No. It is up to you to decide whether to take part. If you decide to take part and change your mind during the study, you can still stop at any time without giving a reason and your rights will not be affected. If you decide to withdraw from the study, all you need to do is contact the researcher using any of the details below.

What will I have to do if I take part?

You will be invited to complete an anonymous case study pertaining to a member of your congregation, attend the community leadership programme and evaluate the workshop over two sessions. Strategic leads will be expected to deliver a presentation at the workshop and take part in a 10-minute audio recorded semi-structured interview.

What are the possible disadvantages and risks of taking part?

The time taken to actively participate

What are the possible benefits of taking part?

There are no direct benefits to taking part. However, you will have the opportunity to learn from the leaders, network with others and apply new knowledge to enable your congregants to use health and care services more efficiently.

What happens when the research study stops?

There will be an evaluation report written for the funders and the findings will be presented at a national conference and in other publications.

What if there is a problem?

If you have any concerns about taking part in the study, or would like to make a complaint, please contact us using the details on page 4.

If you decide to withdraw from the study, then the information you have provided to that point of withdrawal will be used, however, all personal contact details will be destroyed.

Will my taking part in this study be kept confidential?

Yes, all of your information will be treated with the strictest confidence and all legal and ethical considerations will be adhered to

The information you provide will be collected in paper format so that the data can be analysed. However, you will not be identified in the study and any comments you make will be anonymous.

All raw data will be kept safely, and all computer-stored information will be protected with a password only known to the researcher. Your organisational details will be used to form a participant's list

All data collected will be anonymised and it will not be possible to identify you during any part of the study and published work

Who is organising the research?

This research has been organised by Faye Bruce who is a senior lecturer in Nursing at Manchester Metropolitan University and Chair for the Caribbean and African Health Network Greater Manchester

What will happen to the results of the research study?

The anonymised data collected will be kept for five years following the completion of the research study, after this time the data will shredded safely. The anonymised study produced may enable the researcher to submit the work for various publications as journal articles or further research opportunities in the future

Who has reviewed the study?

To protect participants, the study was submitted to Manchester Metropolitan University Ethical review of research process for approval, details of this are can be found at: http://www.mmu.ac.uk/staff/researchers/ethics.shtml.

Research Approval

Address: Faculty of Health, Psychology and Social Care

Manchester Metropolitan University

Brooks Building

53 Bonsall Street

Hulme

Manchester

M15 6BX

Telephone: 0161 247 2510

Email: f.bruce@mmu.ac.uk

If you require further Information

If you would like further information before deciding to take part, please contact Faye who will answer any further questions you may have. You can ask for more time to make your decision

Further information and contact details

If you require more information about this research, please contact the following people:

Faye Bruce

Faculty of Health, Psychology and Social Care

Manchester Metropolitan University

Brooks Building

53 Bonsall Street

Hulme

Manchester

M15 6BX

Email: f.bruce@mmu.ac.uk

Telephone: 0161 247 2510

Thank you for taking the time to read this study information sheet

Appendix C – CLP Invitation Flyer

Manchester Metropolitan University

CAHN
Caribbean & African Health Network
Greater Manchester

Community Leadership Programme

What is the Community Leadership Programme?

This award winning Mary Seacole initiative has been designed to enhance faith leaders knowledge of the health and care system.

The aim is to provide faith leaders with the information they need so that they can effectively navigate the health and care system, influence decision making and improve access to health and care services for their congregates and local community.

Why develop this programme?

Faith Based organisations are important institutions in the Caribbean and African Community and one where people feel they can go to for guidance. It is therefore important that our faith leaders are equipped with knowledge of the health and care system and services so that they are able to provide guidance and support to their congregates and local community.

Empowering faith leaders with knowledge to improve access to health and care services

What will happen during the programme?

- Presentations by leaders from across health and care services
- Attendance at a one day workshop
- Discussions using real life case scenarios
- Networking
- Two one hour follow up focus group discussions 6 weeks apart. Dates to be confirmed
- Refreshments will be provided during each event

Date and Time and Venue of Session 1

19th March 2018
10.00am - 16.00pm
(9.30am registration)

Chancellors Hotel, Chancellors Way,
Moseley Road, Fallowfield,
Manchester M14 6N

Contact Details: Senior Lecturer Nursing, Programme Lead, Faculty of Health, Psychology and Social Care
Manchester Metropolitan University | Tel: + 44 (0) 161 247 2510 | Email:f.bruce@mmu.ac.uk

Appendix D – Community Leadership Programme Schedule

Monday 19th March 2018

Community Leadership Programme Training Day

Time	Presenter	Content outline
9.30	Registration	Tea and Coffee and pastries
10.00	Faye Bruce	Introductions Listening, questioning and learning
10.15	[redacted]	Welcome Presentation —Faith in Health Care
10.30		The Community and Faith sectors engaging in the task of transforming GM Health and Wellbeing
10.35		GP Member Manchester Health & Care Commissioning Board – Primary Care reform in GM and access to primary care services
11.05		Director of NHS Trust Access to 7-day Hospital Services – 10 Clinical Standards
11.20		Questions and Discussion (using flip charts
11.45		Lunch
12.30		
12.45		Case studies discussions
13.00		Early Intervention in Psychosis services across Greater **Manchester** Mental Health Access to Mental Health Services
13.30		Councillor - Local authority and Social Care services. Leadership and Decision Makers Approach - Enabling an inclusive Health and Wellbeing Board to deliver NHS, Public health, Social and Children's Services.
13.45	Nevile Levy	GM Ambulance Service
14.00		Discussion from presentation
15.00		Break
15.15		Challenges, Opportunities, Implications
15.45		Reflections from the day, next steps & close

Dates for focus group and evaluation

Appendix E – CLP Case Study Template

Please provide some background information of the Client – no names here
Example. How old are they, do they attend your organisation. Do they live alone? do they have family support? Do they practice a religion? Has anything happened such as time spent in an institution – e.g. prison
What are the health and care needs of the Individual?
Example - What is the health condition/diagnosis. How did they find out about the health problem, hospital or GP diagnosis?
What Health and Care Services have been accessed so far?
Example - Hospital, Community Services, GP practice, mental health services, palliative care services etc, Macmillan
Are the Health and Care needs being met or have there been any barriers?
Example: Referral, time delays, poor communication between services

Community Leadership Programme Case Studies

Case Study example

Please provide some background information of the Client – no names here
Example. How old are they, do they attend your organisation. Do they live alone? do they have family support? Do they practice a religion? Has anything happened such as time spent in an institution – e.g. prison **A year-old female, lives in supported semi-independent accommodation in the community but under a CTO.** **Lives alone in her own flat however in a building that accommodates 3 other individuals each person living independently with 24 hours staff support. Though support provided by staff is very minimal. It includes ensuring that individual is engaging with support and compliant with medication and also to monitor sign of relapse.** **This individual is often visited by elderly parents and sister who also support her in shopping and getting to her appointments. She is very dependent on her family and support workers believe this may have an impact on her ability to engage with staff and other support services.** **Over the last ten years of her life she has mostly been in institutions recent attempt to live within the community has not been very successful. Individual has said she belongs to the Church of England but has not had a lot of opportunities in the last few years to engage in that regards due to relapse.**
What are the health and care needs of the Individual?
Example - What is the health condition/diagnosis. How did they find out about the health problem, hospital or GP diagnosis? **Individual has a long term enduring mental health condition and a diagnosis of schizophrenia but sometimes achieve optimum health however has also suffered several relapses and has to be recalled back under section 17a on occasions.**
What Health and Care Services have been accessed so far?
Example - Hospital, Community Services, GP practice, mental health services, palliative care services etc, Macmillan

Mental health assessment and recovery team. GP, has allocated CPN.
Are the Health and Care needs being met or have there been any barriers?
Example: Referral, time delays, poor communication between services **To some extend Health and Care needs are meet but barriers include non-compliant, non-engaging and time to get appointments for mental health review. Also, poor communication between the care team and the mental health team and poor contact route with allocated CPN, there is no direct contact it has to go through the Mental Health Team which can be delayed.**

Please provide some background information of the Client – no names here
Example. How old are they, do they attend your organization. Do they live alone? do they have family support? Do they practice a religion? Has anything happened such as time spent in an institution – e.g. prison The individual is a Black Afro-Caribbean female, in her early forties, is single, has no children and is a university graduate with Honours. She is an active member of our religious organization and a member of a local community in Manchester. Additionally, she is a former administrative officer, a job which created undue pressure to which she succumbed and became unwell. Although she lives alone and is provided with council housing, she is greatly supported by her parents, extended family members and her church friends. This support is supplemented by being gainfully employed one day per week full time and with part time shifts when needed. Her medical condition has led to her being admitted to the psychiatric unit on at least two occasions.
What are the health and care needs of the Individual?
Example - What is the health condition/diagnosis. How did they find out about the health problem, hospital or GP diagnosis? Having been admitted to the mental health unit, she was diagnosed as being psychotic by the psychiatrist. As a result, she has been put on appropriate medication to aid her in coping with the impact of the psychosis. For example, she sleeps for long hours, becomes lethargic often and experiences auditory hallucinations, mainly the hearing of voices. The prolonged bouts of sleep prevents her from being as physically active as she would like to, seeing she hardly plays sports or engages in aerobics as was previously the case prior to becoming ill.
What Health and Care Services have been accessed so far?
Example - Hospital, Community Services, GP practice, mental health services, palliative care services etc, Macmillan This young lady presently attends her psychiatric consultant's practice for reviews on her progress and of her medications on a regular basis. At times she visits her GP practice for less urgent needs.
Are the Health and Care needs being met or have there been any barriers?
Example: Referral, time delays, poor communication between services Although she receives regular reviews by her psychiatrist and is actively engaged in a group activity in her local parish church, she believes that her work establishment is discriminatory, uncompassionate and shows little regard for her as a person. Thus although, she desires to and can work full time, the management continues to refuse to respond to her request for more days to work to supplement her finances. This is a critical barrier within the social model of disability which has to be manoeuvered carefully in such a way that there is less negative impact on this young lady. In spite of these challenges, she approaches me as her Christian pastoral leader about

various situations for which I provide Christian pastoral care through counsel, guidance, and prayer.

Additionally, I provide support by accompanying her on the review visits. She also attends the weekly prayer services where congregants share their challenges for which theological reflection is provided so that she and others can put meaning to the experiences. In such services, prayer and the study of the Sacred Scriptures also occur. The family service on weekends provides a further opportunity for her to worship meaningfully and fellowship positively through prayer, study and worship. Also it allows her to bond with her fellow congregants over a communal lunch, thus giving her a sense of belonging and by extension, enable her to refocus her thoughts on other helpful activities. These spiritual disciplines and activities provide a positive impact on her life and her wellbeing, thus enabling her to function well. For example, this young lady is able to maintain her home well, manage her finances by do her own shopping, paying her bills and also being employed at a food establishment.

There is a Day care programme for the elderly at the church where she volunteers one day per week. For her benefit, a mental health support group has also being set up with the aim of assisting individuals like her in maintaining their emotional and mental balance.

Her mother is very supportive by keeping in contact daily, and providing moral and financial assistance when necessary. For instance, she visited the Caribbean with her mother where she spent six months. A change of climate and environment boosted her morale from which she became energetic and lively.

Such formal and informal social and spiritual structures, as set up by her religious organization, have contributed to her being more settled and not undergoing any hospital admissions for at least three years.

Appendix F - Focus Group Questions

Faith Leaders - Reflect on the leadership learning day, what were your experiences

- What learning took place for you?
- Why did you take part and what did you think you would accomplish when you accepted the invitation?
- Did you encounter any challenges? If so, how did you seek to address those challenges?
- What did you learn from the public sector leaders across health and care services experiences?
- Did you find the setting for the workshops appropriate?
- What feedback can you provide on the overall engagement of public sector leaders with you as black faith leaders
- What elements of the programme were most useful to you as a faith leader and member of the black community?
- Were any elements not useful to you in your role?
- How can this programme be enhanced to achieve its objectives for engagement of black faith leaders in strategic decision-making?

Appendix G – CLP Semi – Structured Interview Schedule

Strategic Sector Leads

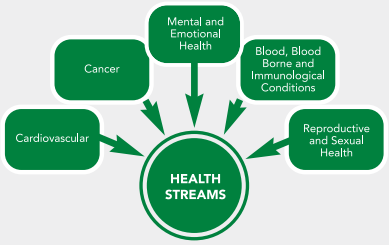
1. What were your views when being asked to take part in the programme?
2. How you prepared for the programme?
3. Did you have any expectations from the day?
4. Would you do it again, and did you get the right amount of support to participate?
5. Tell us whether you think your input was successful against the brief to improve health knowledge?
6. What elements of your session do you think worked well, what didn't work so well?
7. What could be improved?
8. Any thoughts and further recommendations and or comments?

Appendix H - The Caribbean and African Health Network (CAHN) Greater Manchester Flyer

CAHN
Caribbean & African Health Network
Greater Manchester

CAHN is a non-profit organisation whose vision is to transform the way the Caribbean and African Community access information and resources that enable them to improve their holistic health and well-being.

Our passion is to reduce health inequalities and to ensure that services for the black community are culturally appropriate.



Services:

- Community Engagement
- Research
- Education and Training
- Strategic Stakeholder Engagement
- Organisational Development
- Advocacy

Lead | Educate | Support | Advocate | Enhance

For further information contact: info@cahn.org.uk Telephone: 07853 556 591
Follow us on: cahn @cahn_gm