Minding the gaps

Are BME groups partners
or substitutes in health provision?

Research into the participation of BME organisations and groups in health consultations and activities in Kensington, Chelsea and Westminster

A Report by the BME Health Forum
June 2006

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Acknowledgments

The BME Health Forum would like to thank all the groups and organisations that participated in this project. It is these groups that have made this project possible.

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This report has been written by Nafsika Thalassis, Project Co-ordinator, and Amjad Taha, BME Health Forum Manager.

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Acronyms

BME	Black & Minority Ethnic
BMEC	Black & Minority Ethnic Communities
DH	Department of Health
Forum	The BME Health Forum
KCW	Kensington & Chelsea and Westminster
K&C PCT	Kensington & Chelsea Primary Care Trust
PBC	Practice Based Commissioning
WPCT	Westminster Primary Care Trust

Summary

Aims and objectives

To identify BME organisations who have not participated in public consultations and health activities. To canvass the views of BME organisations that have participated in such activities about the value of participation. To obtain the perceptions of BME organisations regarding the health issues that concern their communities.

Methodology

Two hundred groups and organisations in KCW were interviewed by specially trained volunteers nominated by BME organisations.

Public Consultations

Our results showed that many organisations are confused by the word 'consultation'. While 101 organisations (50.5%) reported having taken part in a consultation it transpired that many were referring to workshops that provided information e.g. TB seminars rather than health policy/service consultations. Moreover, it appears that the PCTs and NHS Trusts, do not keep records of public consultations or make clear distinctions between what constitutes a consultation and what are information giving sessions. It is therefore not possible to assess the effectiveness of particular consultations from the perspective of the BME communities.

However, only 18 organisations said that they did not participate in consultations because health was not a priority for them while 68 organisations said they did not participate because they lacked information about consultations. This suggests that consultations would be much better attended if they were more effectively publicised.

The conclusions and recommendations to the PCTs and NHS Trusts are:

- Tackle the confusion surrounding the term consultation, i.e. be clear about what constitutes a formal consultation and what constitutes information-giving or promotional events.
- When consulting, PCTs and NHS Trusts should state very clearly that they are seeking the public's views and what it is they are consulting about.
- Address the apparent lack of confidence in their intentions to listen to the views of BME communities.
- Develop proper structures for feeding back and demonstrate that participation in consultation influences policies and decision-making.
- Publicise consultations more effectively amongst BME communities and communicate information in the right format at the right time.
- Inform the community about the outcomes of consultations and the effect on local services.
- Keep records of consultations, including details about participation of BME communities so they can monitor the participation of various communities.

Engagement with the BME Health Forum

Out of 200 organisations, 84 (42%) indicated that they had participated in BME Health Forum activities. However, 175 organisations (87.5%) said that they would like to attend the Forum's meetings and events in the future.

The BME Health Forum has been successful in reaching out to BME communities in KCW. However, the feedback received highlights that there are some communities who have not been sufficiently involved in the Forum activities. The Forum now has appropriate data with which it can widen participation.

Health Activities in the community

Overall the vast majority of organisations in KCW (179 organisations, 89.5%) are involved in health activities. The organisations least likely to be involved in health activities are supplementary schools.

There are a variety of health related projects run by BME community organisations mainly around mental health and wellbeing, access to health services, physical activity, hospital and home visits for ill people, and healthy eating.

The PCTs' priorities and funding schemes influence these results. In particular, a large number of projects involving physical activity are funded by the PCTs. In contrast, projects around access and other essential support such as home and hospital visits are far less likely to be funded. Nonetheless, many groups clearly consider these activities to be a priority and a number of organisations are supporting people register with a GP, interpret for them and offer support through the system when things go wrong. The fact that these activities are continuing despite little or no funding indicates the level of real need and commitment in the community.

Conclusions and recommendations to NHS Trusts from this section are:

- The priorities of BME communities, especially regarding access to services, must be properly catered for when designing and delivering health information and awareness sessions.
- Supplementary schools must be targeted in their campaigns and included in the Healthy Schools programmes.
- The NHS must work with BME organisations as partners and service providers, particularly in the light of the introduction of "Commissioning a Patient-Led NHS" and "Practice Based Commissioning". Community-based groups and organisations play a crucial role in improving the health of their communities and for many BME communities their community-based group is their gateway to accessing public services.

Interest in developing further projects

Out of a total of 200 organisations 179 (89.5%) would like to develop further health related activities. This shows that BME groups consider health as a key issue for their communities and are interested in addressing it by developing health activities and projects. BME organisations can therefore play a key role in improving the health of their communities if they are given the necessary support to develop their services.

Barriers in developing further activities

Lack of funds was the most significant barrier as it was mentioned by 133 organisations (66.5%). Lack of staff and lack of space are also important (58 organisations, 29%; 36 organisations, 18%). Few organisations found lack of interest from the community a problem in developing projects (20 organisations, 10%).

Health Concerns

Access to services, GP practices in particular, is the single most important health concern reported by community organisations. Problems about accessing health services were mentioned by 110 organisations (55%). Arguably, the persistence of this issue over so many years indicates a fundamental flaw in the way PCTs have dealt with it so far. The steady increase in spending on interpreting and translation services in KCW over the last few years has been necessary, important and welcome. However, overcoming the language barrier cannot be dealt with in isolation of the other aspects of access to services, i.e. interaction with GPs and registration. The fact that access is still a major health issue to so many BME organisations shows that without adopting a holistic approach to this issue, real change will remain out of reach.

In terms of Health Conditions and Lifestyles, mental health and wellbeing is the most pressing health concern in BME communities. Other major health concerns included diabetes, sexual health and HIV, high blood pressure, substance misuse and heart disease.

The conclusions and recommendations from this section:

- The focus of the PCTs and NHS Trusts should be on addressing the gaps and weaknesses in services. This should include raising awareness of access issues and training provision amongst health professionals, especially GPs, practice managers and

receptionists. While, patient education and developing the BME communities' understanding of health provision is important and should be catered for, the focus must remain on the need to examine all aspects of access to ensure that needs are met.

- Ethnicity data: collection of ethnicity data at primary and secondary care levels is essential to understanding inequalities in access to health services.
- Mental health: The fact that a large number of BME organisations are concerned about mental health and wellbeing underlines unmet needs and gaps in service provision in KCW. This issue and the recommendations about how to respond to it were the subject of the Forum's previous report (2004/05) "Caught Between Stigma & Inequality".
- Diabetes: it is a major health issue for many BME communities. Therefore, developing services for the treatment and management of diabetes in the community is necessary to meet this need.
- In addition, this research has identified other major health concerns for BME organisations in KCW, including blood pressure and heart disease, substance misuse, obesity and others. This data will enable the PCTs and NHS Trusts to identify community groups in order to work with them to ensure that services are available to them.

Unregulated Migrants

During our research, we found that many organisations provide a wide range of health related services to unregulated migrants (include failed asylum seekers, overstayers, and others who are in breach of UK immigration regulations). These services include counselling and support for mental wellbeing issues, support in accessing services, interpreting, and information on various health issues. These organisations talked of the very serious distress that unregulated migrants suffer which is related to immigration problems and the associated lack of access to NHS services.

This humanitarian issue needs to be addressed. From a pragmatic perspective, the lack of access to primary care services faced by unregulated migrants increases pressure on A&E and hospitals, because minor health problems that could be easily and cheaply dealt with at primary care level are allowed to develop into emergencies. Currently, the government accepts that unregulated migrants are entitled to emergency health care on a humanitarian basis but has limited their access to primary care. This undermines other efforts to make NHS services seamless and promote community based services. It is clear, that this situation cannot be allowed to continue and that the DH need to ensure that this group, has full access to NHS services.

Next Steps

To take this report forward the BME Health Forum will be working with the PCTs, GPs and stakeholders in order to develop policies and structures to address the health needs of BME communities and to ensure that these communities are properly involved in the planning and commissioning of health care in the area.

Furthermore, it will develop projects and task groups to address some of the findings of this project. Concern about access to GPs, which is one of the main findings of the report, will be addressed by a project that will be developed by the Forum in due course to improve access to GP services for people from BME communities.

Moreover, the Forum recognises that it has not been able to reach out to and involve some BME communities due to lack of capacity. Therefore, involving new communities in our work is one of our priorities for the next year and efforts will be made to engage with those who have not been involved in the past.

Introduction

In March 2005, the BME Health Forum launched the **"Research into the participation of BME organisations in health consultations and activities in K&C and Westminster"** project.

The purpose of the project was to widen the participation of black and minority ethnic (BME) communities, in KCW, in public consultations and activities aimed at improving the health of BME communities. To achieve that, the project had the following objectives:

- To identify BME organisations and groups[1] in the two boroughs, who have not participated hitherto in the public consultations and activities around health issues that affect their community.
- To investigate the possible causes of non-participation of those organisations.
- To canvass the views of those organisations who have been active in local health forums, about the value of such participation and the barriers, if any, that they experience.
- To obtain, from those organisations contacted, their perceptions of what might be the health issues facing their communities and the barriers individuals face in accessing health services.

The project was set up to achieve the following outcomes:

1. An up-to-date database of BME organisations in the two boroughs.
2. A greater understanding of the reasons why organisations do not participate in health related activities and consultations.
3. An assessment of the efficacy of current, health-related public consultation from the point of view of BME organisations.
4. An overview of what different community groups identify as the key health issues for their members.
5. A strategy for achieving wider participation of BME organisations in public consultation on health issues and in health related activities.
6. Training of a cadre of volunteers to become community health researchers.

Launch of the project

This report sets out the findings of 200 interviews carried out with organisations.

Policy and Legislative Context

This project, along with previous task groups and projects co-ordinated by the BME Health Forum, came about in the light of recent legislative and policy developments that require PCTs and NHS Trusts to consult and engage with their local communities. The legislative and policy requirements are as follows:

Section 11, Health & Social Care Act 2001

Requires every NHS body, e.g. PCTs and NHS Trusts, as of 1 January 2003, to make arrangements to ensure that people for whom services are being, or may be, provided, are involved and consulted, either directly or through representatives, on the planning and provision of services; and on the development and consideration of proposals for changes in the way these services are provided and on the way decisions, which affect services, are made. This statutory duty means that PCTs and NHS Trusts have to consult and involve local communities, not just when a major change is proposed, but also in ongoing service-planning; not just in the consideration of a proposal, but in the development of that proposal; and in decisions about general service delivery.

Race Relations Amendment Act 2000

[1] Within the report, the terms "groups" and "organisations" are used interchangeably. While the majority of the groups that were interviewed had a formal structure and thought of themselves as "organisations", a number of subgroups and informal groups were also interviewed. For further clarification see section 1, p.12.

This Amendment, resulting from the Stephen Lawrence Enquiry, adds to the general duty to eliminate racial discrimination and promote equal opportunities, by specifying the creation of a Race Equality Scheme aimed at preventing 'institutional racism', and ensuring that the UK's racial diversity is properly represented at all levels. The aim is to help public authorities provide fair and accessible services, and to improve equal opportunities in employment. The Act intends that race equality shall be 'mainstreamed' within the organisation; in other words, that attention to equality is built in to all its policies, at all levels and at all stages. All Public Bodies are required to produce a *Race Equality Scheme* outlining their process to improve delivery and equality in their services, and to involve local communities in this process. The challenge is to mainstream this process to ensure that race equality is a central part of mainstreamed service -provision, commissioning and management and that 'impact assessments are carried out to demonstrate this is the case.

Commissioning a Patient-Led NHS (CPLNHS)

In May 2006, and as part of changes in the NHS structure, the Department of Health (DH) defined three main functions for the PCTs:

1. **Engaging with its local population** to improve health and well-being;
2. Commissioning a comprehensive and **equitable** range of high quality, responsive and efficient services, within allocated resources; and directly providing high quality responsive and efficient services where this gives best-value;
3. Directly providing primary and community-based services (and for Care Trusts, adult social services), where the PCT's commissioning function shows that direct provision of such services is best for patients and also provides best value for money for taxpayers.

This means that PCTs:

1. Have to perform their functions for, and with, their local population, **in pursuit of equality**, quality, responsiveness, innovation, efficiency and affordability.
2. Have to lead their local health system; and develop, and deliver their functions through, **effective partnerships** –particularly practice-based commissioners and with Local Authorities begin developing Local Area Agreements with Local Authorities as well as the full range of different types of providers.
3. Have to hold providers to account through commissioning and contracting.
4. Are **accountable to their local population** directly and through Health Overview and Scrutiny Committees (OSC); and to Strategic Health Authorities. PCTs operate within the framework of Department of Health policy; they are held to account for this by SHAs, not directly by the Department. The PCT provider function must be clearly separated from the PCT commissioning function from Board-level down; the latter holds the former to account for delivery.

Methodology

Project Stages

The project included the following stages:

1) Preparation of a brief for tendering to consultant trainers.
2) Selection of consultant trainer.
3) Recruitment of volunteers for training and research.
4) Training of volunteers.
5) Field research: interviews/one-to-one sessions with group representatives.
6) Information collated and written up.
7) Report drafted, commented on by Steering Group, published and launched.

Selection of consultant trainer

Trainers were recruited on the basis of the following brief:

- Train volunteers to undertake the research work.
- Empower volunteers to go out and achieve the objectives of the project and report back on progress.
- Review the questionnaire and advise on revision to meet the above objectives – revising in consultation with the volunteers.
- Brief volunteers on using the questionnaire.

- Develop a method of certifying the suitability of each volunteer, who has completed training.

Individuals or organisations interested in delivering this training were asked to submit a draft project plan and a suggested training programme, including timescales and costing. They were also asked to provide initial comments on a draft questionnaire, which had been prepared earlier.

It was essential for the selected trainer to have experience of social research and it was desirable to have experience of working with BME communities, as all the volunteer trainees are from a BME background, including asylum seekers and refugees.

The recruitment and selection of volunteers

To ensure that our group of volunteers reflected the diversity of KCW, the BME Health Forum advertised its plans to recruit volunteers amongst BME community groups in KCW. Groups were encouraged to nominate their volunteers/members but self-nominations were also accepted. Thirty applicants were interviewed and twenty-three volunteers were selected.

(For details about who the volunteers are, please see appendix A)

Personal Requirement

Each of the selected volunteers had to fulfil the following requirements:

- was a member of a black & minority ethnic community, including refugees or asylum seekers.
- could speak, read and write in English to the required standard for this project and, preferably, in one community language.
- was not in full time employment.
- was concerned about and had some insight into health issues in their own community.
- had good interpersonal communication skills.
- was willing to learn, undertake training and work as part of a team.
- was committed to undertake the required work (10 interviews or more) between August – November 2005.

Volunteers' graduation ceremony

Benefits

By taking part in this research project, volunteers:

- were provided with professional training on how to conduct social research.
- were awarded a Certificate of Attendance on satisfactory completion of training.
- had their training travel expenses reimbursed.
- were paid £15 for each interview including expenses.
- had their contribution acknowledged in all printed material.

Responsibilities & Commitment

Volunteers (appendix A) were required to:

- attend the two-day training programme and any follow-up meetings.
- satisfy the programme organisers that they had acquired the necessary skills.
- conduct interviews and fill in questionnaires with up to 10 BME organisations in KCW.
- conform to requirements of quality control and monitoring.
- translate questionnaires and transcribe interview recordings (if applicable).
- send completed questionnaires to the BME Health Forum.
- actively promote the project and encourage as many groups as possible to take part in it.

The training programme

This was a two-day intensive programme in the methodologies and techniques of qualitative research, as applied to health and social care. Research techniques taught to participants enabled them to research the participation of communities in public consultations and in activities aimed at improving the health of the local population. Participants also studied methods to investigate the

causes of non-participation by community groups, techniques to investigate health issues facing their communities and the barriers individuals face in accessing appropriate health care.

Development of the questionnaire

The questionnaire (Appendix B) was developed in stages. The first draft was written directly after the launch of the project in March 2005. The launch event facilitated a discussion on the project about the questions that should be included in the questionnaire. The questionnaire was then amended to take into account some of the comments that were made by the applicant trainers, who were asked to provide their comments as part of their application. In the final stage the questionnaire was reviewed by the trainers and volunteers during the training programme. This review was particularly important to ensure that the questionnaire was understood and owned by the volunteers.

The questionnaire was designed to capture the views, experiences and perceptions of BME groups as well as their involvement in health activities and the health concerns of their communities. Hence, the decision was made early on, that most questions would be open-ended thus giving the interviewees the opportunity to express their views freely without being constrained or influenced by set answers. This meant that the data was more difficult to analyse but also that it reflected more accurately the interviewees' views.

Interviewing

Initially, the interviews were set up by BME Health Forum staff. A list of organisations was put together based on the existing BME Health Forum contact lists, and additional contact lists from other organisations. The main focus was to interview BME organisations, including BME faith groups and mainstream voluntary organisations that employed a worker who focused specifically on BME communities. In addition, some mainstream organisations whose clients were mostly from BME communities were interviewed even if they did not specifically employ a BME worker. A few statutory organisations were also interviewed because they provided services specifically to BME groups.

One of the project's key objectives was to discover new groups that had not previously been involved with the BME Health Forum. To achieve this, it was essential to make full use of volunteers' and our interviewees' knowledge of the community and interviewees were therefore asked to give contact details of small BME groups. As the volunteers gained confidence they began to use this information to set up interviews themselves. An extra training session on how to locate new organisations was provided, which helped the volunteers identify new contacts and build their skills in this area. Some volunteers were thus able to set up dozens of interviews with new groups, which meant that the project gained access to a number of groups which were previously unknown to us. However, some volunteers were more successful in this task than others, and consequently some community groups (typically the community groups of the more pro-active volunteers) have received greater representation than the others.

Support for the project

The BME Health Forum Steering Group formed a subgroup, which included stakeholders from all sectors, to provide support and advice for this project. The subgroup met regularly to discuss the progress of the project and to give advice.

Methodological limitations

The project faced some methodological difficulties. Firstly, the questionnaire was composed almost exclusively on open-ended questions, and therefore relied heavily on the volunteers' skills in transcribing the interviewees' responses accurately. While it was felt that the volunteers were generally able to do this effectively, it is likely that some variance to the results has been introduced as a result. Furthermore, in order to produce quantitative data, the interviewees' responses had to be classified into formal categories, a process which by its very nature introduces some error. Finally, some of the questions in the questionnaire were not as precise as we would have liked. For example, we were unable to ascertain the exact number of organisations who receive funds from the statutory sector (our question was about support which included advice, materials, speakers and training). Furthermore, in our questions about consultations we did not specifically ask whether groups that did not attend consultations, did not do so because they could not see the benefits (this option was introduced in our questions about the BME Health Forum).

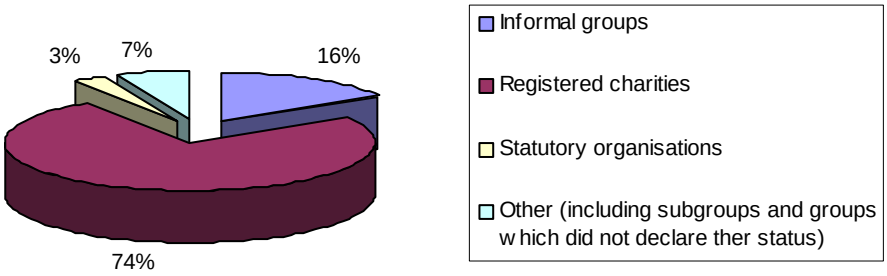
Findings and results

1. The organisations we interviewed

In total, 200 organisations and groups were interviewed (Appendix C). Of these, 83 (41.5%) were based in Kensington & Chelsea, 105 (52.5%) were based in Westminster and 12 (6%) were based in other boroughs. The organisations falling outside the KCW boundaries which were interviewed were located very near to the KCW boundaries and therefore had a large number of KCW users.

The majority of organisations interviewed are registered charities that have received some support (including funds, advice, speakers, training or promotional materials) from the statutory sector. However, there were significant exceptions. In total, 32 (16%) of the organisations interviewed were informal groups, while 6 were part of the statutory sector. Furthermore, 37 (18.5%) organisations had not asked for any support from the statutory sector, while a further 13 (6.5%) had been turned down.

Figure 1: The status of groups and organisations which were interviewed



Although, 148 (74%) organisations reported that they had received some support from the statutory sector, this support was not necessarily funding nor was it necessarily the support that had been requested. Unfortunately, the structure of the questionnaire did not allow respondents to specify precisely what support they had received, however 52 (26%) organisations made the point that although they had received some support it had been less than the amount for which they had applied.

Support status	Number of organisations
Organisations that have asked for support from the statutory sector	163
Organisations that have asked for funds from the statutory sector	151
Organisations that have received some support from the statutory sector	148
Organisations that have been refused support from the statutory sector	13
Other[2]	2

Table 1: Support from the Statutory Sector

[2] This category includes one group who did not answer the question and one group that had not yet heard back about whether they had received support.

The majority (143 organisations, 71.5%) of the organisations that were interviewed were BME community organisations. These included 17 women's organisations and 12 supplementary schools. In addition, 34 mainstream charities, 17 faith organisations, and 6 organisations that are part of the statutory sector were interviewed. The mainstream organisations were interviewed on the basis that they employed a worker specifically to work with BME issues or had an overwhelmingly high proportion of BME users. The faith organisations that were interviewed included a majority of Christian churches from various denominations with Latin American, Filipino, African and Arabic congregations as well as two Mosques, a Buddhist temple and a Sikh temple. A number of the community organisations that were interviewed catered for a specific faith group - (Muslim and Jewish) but since they were not primarily faith organisations they were categorised as BME community organisations.

2. Public consultations

The aim of this section was to establish the level of BME community groups' participation in public consultations organised by PCTs and NHS Trusts. We also aimed to have an understanding of how groups regard the usefulness of those consultations in terms of being able to have influence.

2.1 Participation in Consultations

This section has highlighted that many organisations are very confused by what is meant by the word 'consultation'.

In response to the question **"Have you participated in any health-related public consultation by a hospital or a Primary Care Trust?"** 101 organisations (50.5%) responded that they had. However, when asked what the consultation was about, many groups described events organised by PCTs or hospitals such as workshops or seminars, which provided information about TB or flu jabs rather than health policy/service consultations. In order to tackle this problem we asked the PCTs to provide us with a list of formal consultations, which we could use to identify the organisations that had taken part. It transpired that no such lists were kept by the PCTs. Moreover, it appears that the PCTs do not make clear distinctions between what constitutes a consultation and what are information giving sessions. This suggests that the confusion in the community about what constitutes a consultation reflects a lack of clarity within NHS organisations. Therefore it is not possible for local NHS bodies to assess the effectiveness of particular consultations from the perspective of the BME communities and the actual number of organisations that have participated in consultations cannot be estimated.

In addition, because a number of organisations are staffed exclusively by volunteers and suffer a high staff turn over, it is possible that a number of organisations may have participated in consultations in the past without the particular interviewee being aware of it.

2.2 Usefulness of Consultations

Since it has been impossible to identify which of the events mentioned by the organisations interviewed were formal consultations, it has been difficult to assess how useful consultations have been. However some points were highlighted:

Information sessions are generally considered to be very useful. Sessions about antibiotics, cancer, diabetes, first aid, flu jabs, healthy eating, high blood pressure, sexual health and HIV, smoking cessation, substance misuse, TB, and women's health were invariably described as very good. A health day event in a Chinese organisation that used a Chinese interpreter also received positive feedback.

More generally, consultations are seen as a good way to find out more about the statutory sector and to network with other organisations. For example St Mary's summer fair was described by a Bangladeshi Women's organisation as ***"very useful for us because we had the opportunity to meet other groups and organisations"***. A consultation on mental health with Tower Hamlet's PCT was described as useful by a London-wide Bengali organisation because ***"we found out the framework of how the PCT works and how the needs of the Bangladeshi community needs were identified and the services delivere***d". The review of the London HIV Commissioning Strategy also received positive feedback from an HIV organisation which said that ***"It allowed real***

people to be informed about the NHS' direction in the future". A consultation described as being about ***"what the PCT was doing and activities for the future"*** was described as ***"very useful because you pick up a lot of things and update information"***. These comments are similar in that although the organisations are identifying the process as useful, they do not regard it as an opportunity to influence the PCTs or Trusts but merely to absorb information.

A handful of consultations were perceived in a more positive light. A consultation between a BME diabetes organisation and Westminster PCT was described as ***"… very useful because they asked us a lot of questions about what's going on in the community, and consulted us about the contract for the new diabetes centre in Maida Vale"***. A BME health charity described a Department of Health consultation on the Race Impact Assessment of the Mental Health Bill as ***"Very useful as the DH do not normally consult small organisations"***. A Latin American organisation described a consultation with the NHS as mutually beneficial, and an Arabic organisation consulted by the Health Commission about health services in Westminster described the process as very useful.

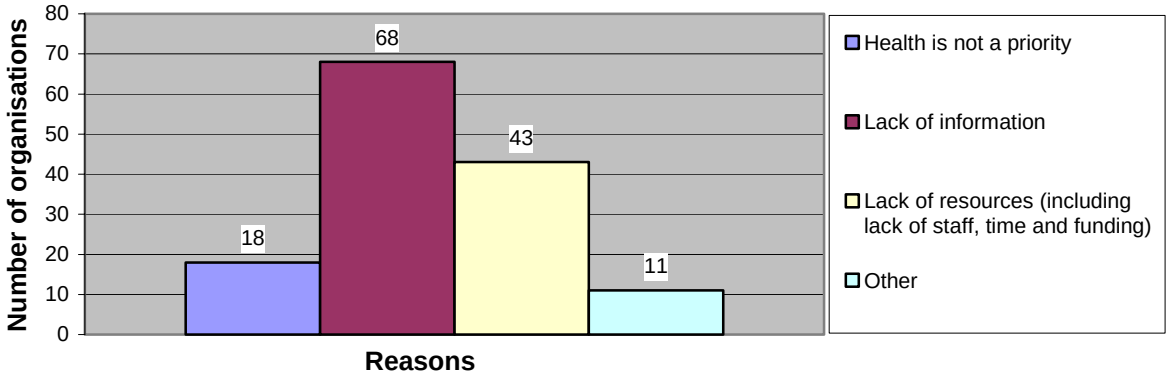
Negative comments about whether consultations were useful included: ***"Useful but no change on ground level"***. ***"No comment"***, ***"No because it was for the benefit of the PCT rather than us"***, ***"Not useful because decision was already made hence formalities"***, ***"Not sure when or if it will be implemented by the PCT"***, ***"Not very useful, because we were the only BME group there and there was nothing specific to BME groups in the final report"***. ***"No they just went through the motions"***.

Perhaps the best summary of the situation is the comment made by a mental health organisation: ***"It was good, provided there will be follow up and outcomes of this consultation will be implemented"***.

2.3 Reasons for not participating

From the organisations that said they had not participated in consultations, 68 (34%) said it was because they lacked the necessary information, 43 (21.5%) said it was due to lack of resources, 18 (9%) said that health was not a priority for them and 11 (5.5%) gave other reasons.

Figure 2: Reasons for not attending consultations



So, the conclusions and recommendations to the PCTs and NHS Trusts from this section are:

- Tackle the confusion surrounding the term consultation, i.e. be clear about what constitutes a formal consultation and what constitutes information-giving or promotional events.
- When consulting, PCTs and NHS Trusts should state very clearly that they are seeking the public's views and what it is they are consulting about.
- Address the apparent lack of confidence in their intentions to listen to people's views
- Develop proper structures for feeding back about how participation in consultation influences policies and decision-making.
- Publicise consultations more effectively amongst BME communities and communicate information in the right format at the right time.

- Inform the community about the outcomes of consultations and the effect on local services.
- Develop a strategy for achieving wider participation of BME organisations in public consultation on health issues and in health related activities.
- PCTs and NHS Trusts should keep records of their consultations, including details about participation of BME communities so they can monitor the participation of various communities.

3. Engagement with the BME Health Forum

Out of 200 organisations, 84 (42%) indicated that they had participated in BME Health Forum activities. However, 175 organisations (87.5%) said that they would like to attend the Forum's meetings and events in the future.

The groups which have participated in the Forum's activities gave a number of reasons for having done so. Primarily, the Forum's meetings are seen as a good way of accessing information and networking with other organisations. Some of the comments included:

"We wanted to know the effect of most common diseases in the community. We want to know more about healthcare in general."

"We felt it was relevant to us"

"We want to be involved and have a say in issues affecting target groups. We feel that our participation will add to the voices of other organisations (BME) and collectively we can be able to shape the future of our services."

"Because we feel our communities are not really covered by the health service in a proper way and that motivates us to attend the Forum's activities so we can make access to our community in terms of health issues"

"Because of the health issues raised by the Forum, working against discrimination."

"My clients are from BME communities, so they encouraged me to participate in such an event to raise their voice."

"It is a means of finding out what's going on in the community."

"It is well organised and it is a useful topic. We wanted to make sure that we do everything possible to reach people across the community and we are interested in the partnership approach and we gain benefits from working together."

"The topics, they are all very important. Also to know how projects are being implemented and their results. Also networking."

"More connections with local BME communities to keep abreast of what is happening."

Some groups expressed confusion about the Forum's independence from the PCT. One group said they attended meetings because they had an ***"interest in BME meeting and wanted to see the difference between BME meetings and PCT meetings"*** while another group seemed to regard the Forum as a good way of becoming informed about the ***"PCT strategies with regard to BME health issues"***. Another group seemed to identify the Forum with the PCT saying that they attend in order ***"to make my contribution to the proceedings of the PCT"***.

The finding that some groups do not distinguish between the PCT and the BME Health Forum was also raised in some of the responses regarding consultations and the questions groups asked the Forum. When asked whether they have attended a consultation organised by a PCT or a hospital, some organisations gave examples of BME Health Forum meetings. Furthermore some groups asked questions about PCT structures and made demands for more funding which indicates that groups are not always completely aware that the Forum is independent of the PCTs

The groups who said they have not participated in BME Health Forum activities gave the following reasons[3]:

Reasons for not participating in the Forum work	Number of groups
Lack of information	69
Cannot see the benefits of joining a policy forum	14
Lack of resources (including lack of staff, time and funding)	38
Health is not a priority	14
Other	4

Table 2: Reason for not participating in BME Health Forum work

A Georgian organisation said ***"This kind of meeting is usually oriented to black and Muslim people / Always the same thing. I don't see what can we get for our organisation."*** Another organisation said they were uninterested in attending because the Forum was specific to KCW, while their organisation is London-wide (but based in Westminster). A religious organisation said they did not want to participate because they wanted to remain independent.

The **conclusions and recommendation from this section:**

- The BME Health Forum has been successful in reaching out to BME communities in KCW. However, the feedback received from this section also highlights that there are some communities who have not been involved in the Forum activities. For example, the Chinese, Eastern European and the Irish communities have not been involved. The Forum needs to address this issue by investing in developing links with these communities.
- The Forum now has data showing which groups have not been involved in its work but would like to be involved in the future. The availability of such data, therefore, will make widening participation in Forum activities a much more focused process.
- The Forum needs to improve how it publicises its activities and meetings to reach out to the many organisations that do not receive our information.

4. Involvement in health activities – current projects

Overall the vast majority of organisations in KCW (89.5%) are involved in health activities. The organisations least likely to be involved in health activities are supplementary schools.

Activities status	Number of organisation
Organisations with ongoing or occasional activities aimed at addressing health issues	179
Organisations with no activities aimed at addressing health issues	21

Table 3: Health Activities in the Voluntary & Community Sector

The majority of the organisations interviewed explained that the "need of the community" was the main reason that they became involved in health issues. Below are some of the answers to the question "What led your group to become involved with health issues?"

"The needs of the community. The voices of the Arabic, Black and Afro-Caribbean group were not being heard. These groups face particular difficulties with regard to the language barrier and culture shock." Mental Health charity in Westminster

[3] Some groups gave more than one reason for not participating in the BME Health Forum activities.

"Users raised health issues during other activities and we found that the mother of all health problems is stress." Afghan organisation in Kensington & Chelsea

"Lack of communication with GP/health services, child care problems, no access to information, poor literacy, also translation of information is too academic." Bangladeshi organisation in Westminster

"The organisation noticed that our members did not have even a basic understanding and knowledge of health care. They have no access to doctors due to their lack of understanding and the language barrier." Chinese organisation in Westminster

"The urgent need for attention to women victims who have suffered all sorts of violence in Eritrean camps." Eritrean organisation in Kensington& Chelsea

"Our members and members of the public approached us with many problems and difficulties they encountered with GPs/NHS, especially things like not being treated respectfully, not being listened to, misdiagnosed, discrimination, lack of information etc, etc." African organisation in Kensington & Chelsea

"The health needs of our community. Emotional and physical needs of sex workers in our community who ask for our help." Christian organisation in Kensington and Chelsea

"The huge number of enquiries about health services from members who because they are illegal do not receive medical care." Community organisation in Westminster

"After observing that many service users do not access the health services. Young mums are not properly looked after. Many do not qualify for statutory health clinics." Refugee organisation in Westminster

"People tend not to access services until they are too ill. Many suffer from PTSD, and are in need of psychiatric care." Charity for homeless people in Westminster

"We would like to involve the community in health issues and to be more aware of health problems. The information from PCT and others led us to be involved." Arabic group in Kensington & Chelsea.

4.1 Information and Awareness

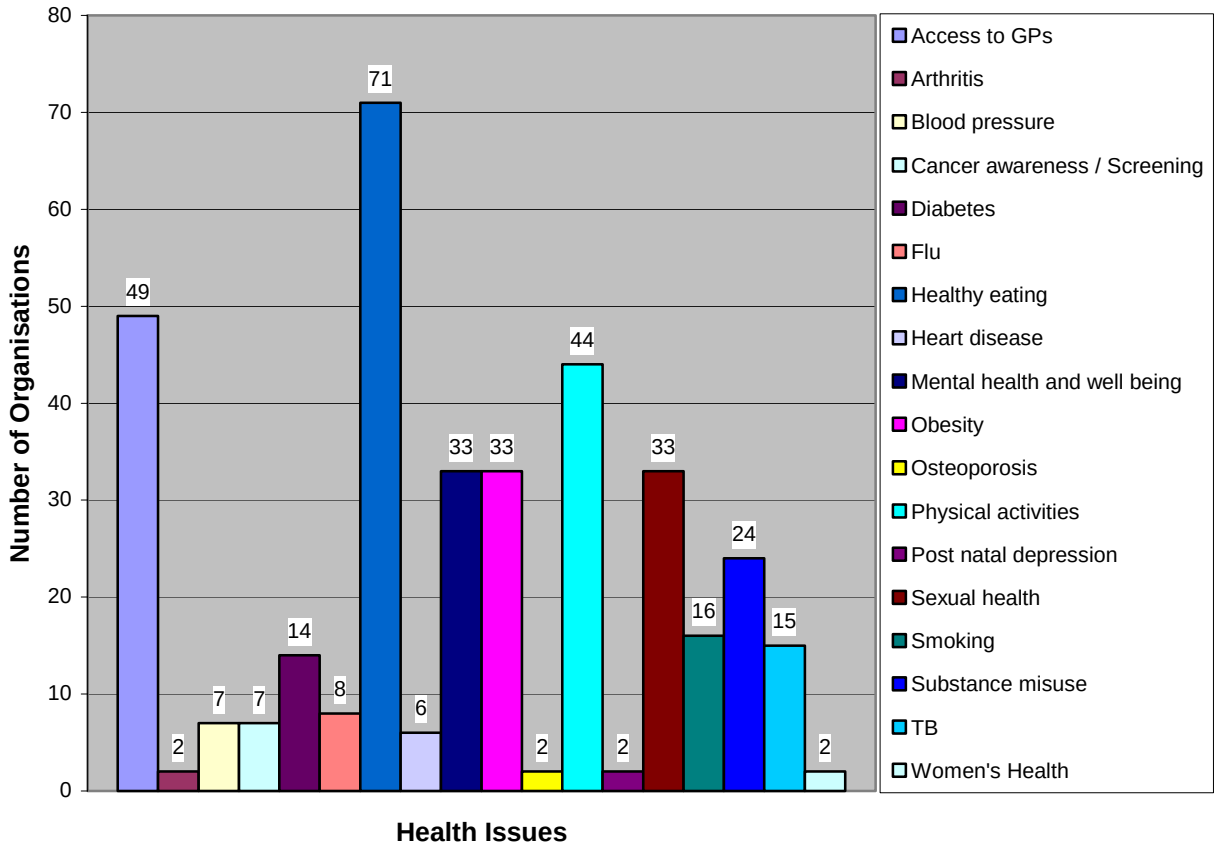
The most common health related activity is disseminating information and raising awareness about health issues, 156 groups (78%) of those interviewed said they provided health information to their members. These include seminars and events supported by the PCTs around TB or Flu as well as information sessions organised by groups mainly about healthy eating, access to health services, physical activities, sexual health, mental health and wellbeing, obesity and substance misuse. Some organisations specialise in one particular area, such as mental health, sexual health or substance misuse.

To a large extent the priorities shown in the provision of information and awareness reflect the priorities of the PCTs. The majority of NHS funded projects about providing awareness and information are about physical activities, healthy eating, mental wellbeing and sexual health. The PCTs are not funding groups adequately to enable them to provide information about accessing services yet this is an area where community groups clearly feel there is a gap in service provision.

Some typical examples of health activities provided by organisations are:

"We try to improve Arab women's access to information and services and to raise awareness of NHS structures and services among the Arab community. We facilitate various health sessions and workshops (breast awareness, prevention of heart disease, diabetes, children and mental health, depression etc)." From an Arabic women's organisation in Westminster.

Figure 3: Provision of Information and Awareness in the Community



"For the last 4 years we have run a women's project where we have offered workshops to improve knowledge around coronary heart disease, diabetes, blood pressure, stroke, HIV & AIDS and sexual health." From an African organisation in Kensington & Chelsea.

"Various projects on: children and families mental health, living with rheumatoid arthritis, breast cancer, post-natal depression, TB awareness, cervical cancer and the importance of smear tests, health and advocacy, improving women's safety, massage therapy." From a Moroccan women's organisation in Kensington & Chelsea.

"We run workshops on teenage pregnancy, domestic violence, psychological support to victims of war." From a Somali organisation in Westminster.

"We try to deal with complaints made about GPs and clinical staff by guiding the clients through proper complaint procedures. Also health awareness sessions." Arabic organisation in Kensington & Chelsea.

"We distribute condoms and HIV/AIDS information to our communities, we encourage people to test for HIV/AIDS, we refer people to appropriate sexual health clinics." Southern African HIV/Sexual Health charity in Islington.

"Diet related disease awareness and STD awareness. We have health professionals from within the community who are helping us run these programmes." From an African organisation in Westminster.

"Health awareness sessions on exercise, heart disease, dieting, osteoporosis, diabetes, menopause, skin problems, arthritis." From a Bengali Women's group in Westminster.

The conclusion and recommendations from this section are:

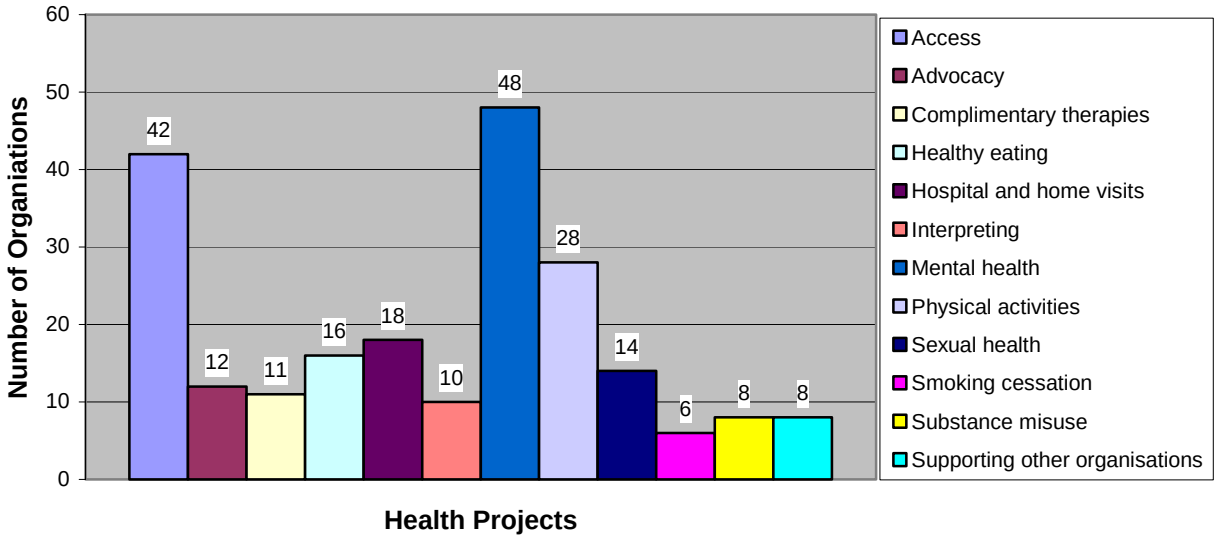
- The priorities of BME communities, especially regarding access to services, must be properly catered for when designing and delivering health information and awareness sessions.
- The above chart provides a valuable opportunity for NHS Trusts to identify gaps in their information and awareness provision. For example, the chart tells us that there is a serious lack of information provision on postnatal depression and women's health within the work of BME groups. If such information is available, it may not be reaching the majority of BME organisations.
- The PCTs should agree an annual plan, in collaboration with BME organisations in KCW, to provide support, advise and training to voluntary and community organisations to enable them to disseminate high quality and effective information to promote health care and reduce health inequalities.

4.2 Health Projects[4]

There are a variety of health related projects run by BME community organisation mainly around mental health and well being, access to health services, exercise, hospital and home visits for ill people, and healthy eating.

The health projects differ to some extent from those of the activities around information and awareness. In particular, healthy eating, which had a particularly prominent role in the activities around disseminating information and awareness has a far less prominent role in the projects while the reverse is true for projects around mental health and well being. This is probably due to the lack of resources faced by organisations that often pushes them to having to choose between providing information or developing a project. How the choice is made will often depend on the issue. So for example, some groups may prefer to have projects around mental health and well being focusing on reducing isolation and providing support or counselling but not provide specialised information on mental health issues. Conversely, some groups may not have the cooking facilities required for a healthy eating project but may find it a lot easier to provide information and awareness about healthy eating.

Figure 4: Health Projects in the Community



The PCTs' priorities and funding schemes also influence the results. In particular, a large number of projects involving exercise are funded by the PCTs. In contrast, projects around access are far less likely to be funded by the PCTs whilst essential support offered by organisations such as home and hospital visits, is never funded. Nonetheless, many groups clearly consider these activities to be a priority. A number of organisations are supporting people to get registered with a GP, interpret for them and offer support through the system when things go wrong. The fact that

[4] Of course there is a degree of overlap between providing information and awareness and actual projects and it is often hard to draw a distinct line between the two types of activities. On many occasions we have classified organisations as both providing information and running a project.

these activities are continuing despite little or no funding, indicates the level of real need and commitment in the community, regardless of funding.

Some of the projects are described below:

"Supporting clients who use the mental health services, listening to their views, and enabling their access to information and other services." Mental health charity in Kensington and Chelsea

"We take people to hospitals and mental health clinics and also visit them there. We provide emotional and spiritual support and guide them through the medical system." Portuguese speaking church in Westminster

"Interpreting in GP appointments. Doctors from our community help those unable to access services." Christian Arabic organisation

"A lot of people can't use NHS services because of discrimination and language barriers. We send people to hospitals, GPs, private surgeries. Health is a big issue." Latin-American organisation in Westminster

"Counselling, spiritual and emotional support, home visits to ill people, hospital visits and help in emergencies due to illness. Interpreting, childcare." Church in Kensington & Chelsea

"Health talk once a month on topics chosen by members e.g. diabetes, high blood pressure, healthy eating etc. We have 8 volunteers who take elderly members to GP and provide transport and interpretation." Vietnamese organisation in Hammersmith & Fulham

"Nutrition sessions for adults and about children's eating, counselling and general health service referrals, parenting skills, breast feeding. Work together with health authorities and health visitors." Asian Women's organisation in Kensington & Chelsea

"We give counselling to both members and non members of the church. We assist them at home in hospital, take them to GPs. We give family support, bereavement courses and food vouchers." Church in Westminster

"We provide interpreters in hospitals, we arrange visits by health visitors, arrange sport activity for elderly people." Polish organisation in Kensington & Chelsea

4.3 Treatment in the Community[5]

Some organisations are offering some forms of treatment in the community. Some of this treatment is clinical and is run in collaboration with GP practices, while in other cases clinical staff from a particular community provide services on a more *ad hoc* basis. Other treatment is more informal – for example, counselling offered by trained volunteers. While some of these services are funded and supported by the NHS, others function independently but are nonetheless supplementing mainstream services.

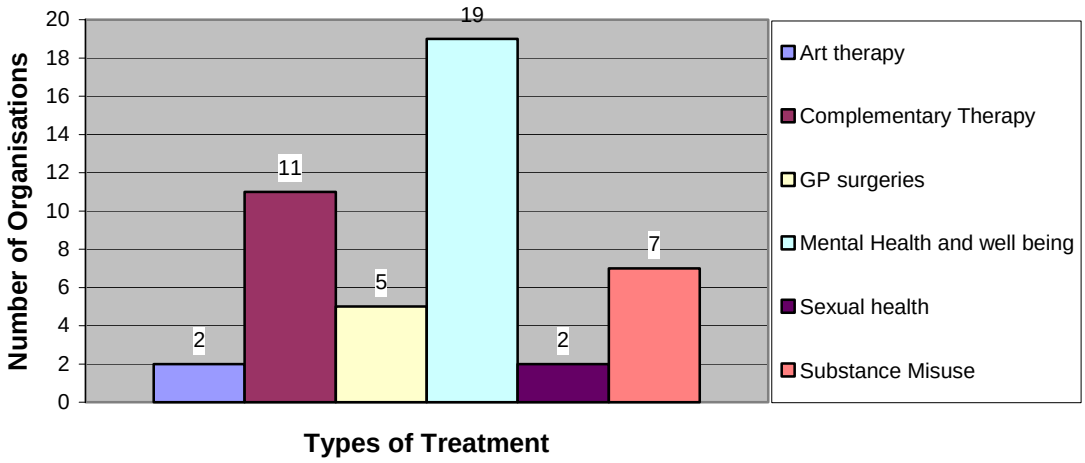
Some descriptions of projects involving treatment in the community:

"We organise health check up sessions (blood pressure, diabetes) by qualified doctors from the community. If they detect something they refer back to GP to ensure person is properly treated. It works both as prevention and raising awareness." Sikh temple in Kensington & Chelsea.

"We provide counselling to victims of sexual violence." Eritrean organisation in Kensington & Chelsea.

[5] The term "GP surgeries" in the chart includes both actual GP practices and the less formal clinical treatments by community doctors. It is thought likely that these doctors are usually GPs.

Figure 5: Treatment in the Community



"We provide a place for elderly Latin-Americans to beat isolation, loneliness lack of self esteem and depression through art therapy. We give advice, information and personal support." Latin-American organisation in Kensington & Chelsea.

"We have a GP surgery but it runs independently. We offer counselling about drugs and alcohol. We offer workshops about health and we have a men's group that meets once a week where 70% of the topics discussed are about health. They also discuss emotional issues and we also have a parents group about the health of children." Charity for the homeless in Westminster.

"Group therapy, individual therapy, marital and family therapy, emergency support to homeless people, community support, first aid, elderly people assistance and support." Church in Kensington and Chelsea.

"Many projects including disability, traditional Chinese medicine, surgery for asylum seekers and refugees, counselling service, smoking cessation, drug and alcohol, healthy cooking. A Chinese GP comes in every Sunday to give advice and help." Chinese organisation in Westminster.

"We have workers specialising in mental health, drugs and alcohol rehabilitation programs, counselling, a primary health care service, a nurse every day and a doctor 3 times a week, a dietician once a week, also homoeopathy, massage, osteopathy, reflexology." Charity for homeless people in Westminster.

"We offer free healthcare to members. There is a GP on hand on Sundays for consultation." Bangladeshi organisation in Westminster.

Conclusions and recommendations to NHS Trusts from this section are:

- To target supplementary schools in their campaigns and to include them in the Healthy Schools programmes. According to the 2001 Census, 43% of children and young people in Westminster and 33% of children and young people in Kensington & Chelsea are from BME backgrounds. As the majority of these children attend supplementary schools at some stage of their childhood, reaching out to those schools will contribute to the health and wellbeing of those children and their families. This will have a considerable impact on reducing health inequalities in the long term.
- Community-based organisations play a crucial role in improving the health of their communities. For many BME communities, their community-based group is their gateway to accessing public services. Therefore, NHS Trusts need to work with those organisations as partners and service providers. This is particularly important in the light of the introduction of "Commissioning a Patient-Led NHS" and "Practice Based Commissioning" so that BME groups are represented as potential service providers.

- To target those organisations which have had little or no involvement in health activities in the past and to support them to participate.

5. Involvement in health related activities - Interest in developing further projects

Out of a total of 200 organisations 179 would like to develop further health related activities.

Organisations want to develop projects around information and health awareness, (promoting a healthy lifestyle, sexual health and HIV, healthy eating, mental health issues, substance misuse, diabetes and high blood pressure, smoking cessation, First Aid), information about accessing support and rights, projects around physical activity, mental health and wellbeing (bilingual counselling, stress management, support groups,) interpreting, GP registration and making complaints, Healthy cooking classes, and domestic violence.

Some examples of activities which groups would like to develop are:

"Running health sessions on a regular basis. Practical cooking sessions. Update women on what's happening on the NHS agenda. Educating women on STDs and the type of education they can get." Women's organisation in Kensington & Chelsea

"Develop an FGM Forum and a consultation on getting GPs to understand the health issues of BME and refugee groups." Women's organisation in Westminster

"To have health professionals visit our centre at a set time and day to bridge the gap, as these domestic workers work 6.5 days a week." Migrant worker organisation in Kensington & Chelsea

"Community led consultation with health professionals" Muslim Faith organisation in Kensington & Chelsea

The **conclusions from this section** are:

- There is huge interest in developing health projects amongst BME groups and that they are willing to develop various projects to meet the PCTs' criteria and priorities. However, PCTs and NHS Trusts must recognise that the priorities of the groups often reflect those of their communities and that projects developed to meet those priorities can better meet their needs and therefore reduce health inequalities.
- The vast majority of BME groups consider health as a key issue for their communities and are interested in addressing it by developing health activities and projects. This leaves little doubt about the role that BME groups would like to play in the new commissioning structure. BME community organisations can play a key role in improving the health of their communities if they are given the necessary support to develop their services. Therefore, NHS Trusts and service providers need to ensure that these groups have the support they need to enable them to be involved Commissioning a Patient-Led NHS (CPLNHS) and Practice based Commissioning (PBC).

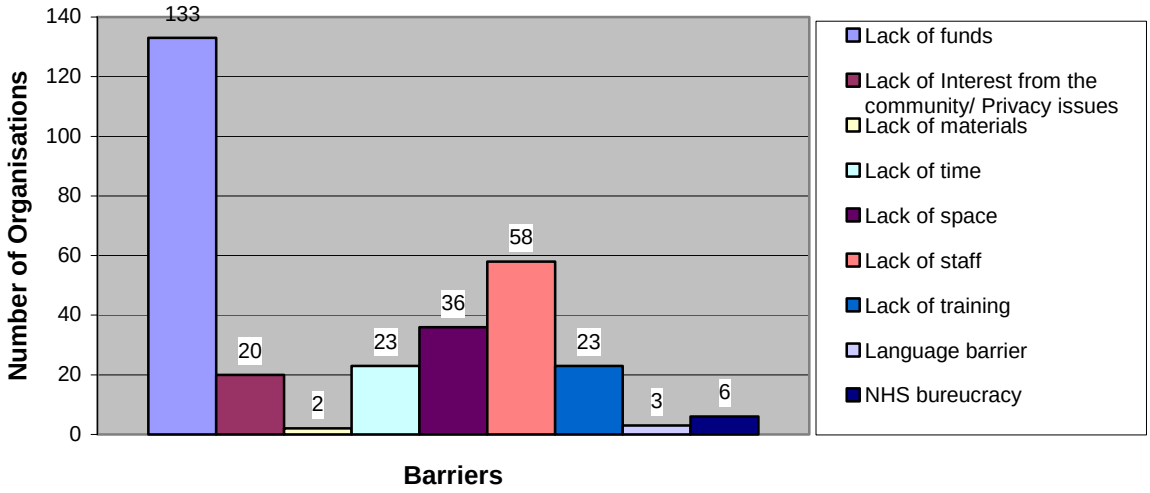
6. Barriers to involvement in health activities

Lack of funds was the most significant barrier mentioned by 133 organisations (66.5%). Lack of staff and lack of space are also important (58 organisations, 29%; 36 organisations, 18%). Few organisations found lack of interest from the community a problem in developing projects (20 organisations, 10%).

It is interesting that 6 organisations mentioned problems with dealing with NHS bureaucracy.

Although these barriers will come as no surprise, this chart provides a much clearer picture of the barriers faced by BME groups which prevent them from playing a more active role in health.

Figure 6: Barriers in developing Health Activities



The following are some of the comments which groups made about the barriers they face:

"Health services are failing to provide the services relating to the Afghan community and information on services is not easily accessible." Afghan organisation in Kensington & Chelsea.

"Funding not enough for sustainability." Community organisation in Westminster.

"The NHS is so large, it is not clear where, when and what to have access to. How and who to approach to get the information you need." Charity in Westminster.

"Barriers are the structure of the NHS." Organisation for migrant workers in Kensington & Chelsea.

"Funding is short-term." Organisation for migrants and refugees in Westminster.

"The PCT themselves do not have any significant funds for activities. We as an organisation do not receive enough to provide vital services." Bangladeshi organisation in Westminster.

Conclusions for service providers from this section:
Unless these barriers are removed, the participation of BME groups in health will remain insufficient, leading to an increase in health inequalities.

The current financial crisis in the NHS may create barriers to increased funding and support. In fact, BME groups in KCW have already started feeling the impact as K&C PCT has decided to suspend its small grants programme for 2006/2007 and WPCT is going through a reconfiguration of its small grants programme (small grants programmes are not BME specific but provide the main source of funding for BME communities' health projects).

However, while BME communities and those advocating on their behalf, such as the BME Health Forum, recognise that the PCTs and NHS Trusts have financial targets to meet, they believe that the health concerns and priorities of BME communities must be taken seriously. PCTs must therefore develop a coherent approach towards funding, supporting and working with BME groups. The current situation seems to generate from:

- A lack of understanding of the importance of the role BME organisations play within their communities.
- A lack of understanding and recognition of how health projects and activities developed and run by community-based groups can be much more successful in addressing the needs of their members than those developed and run by statutory sector agencies.
- A lack of effective engagement with BME organisations that enables the views of the communities to be represented in policy and decision-making at all levels.

These barriers will continue until the approach of PCTs and NHS Trust moves towards adequate inclusion of BME groups in policy development and local decision making. PCTs, GP practices and hospitals must seize the opportunity that "Commissioning a Patient-Led NHS (CPLNHS) and Practice Based Commissioning offers to work with the BME groups as partners and service providers or health inequalities will continue to grow

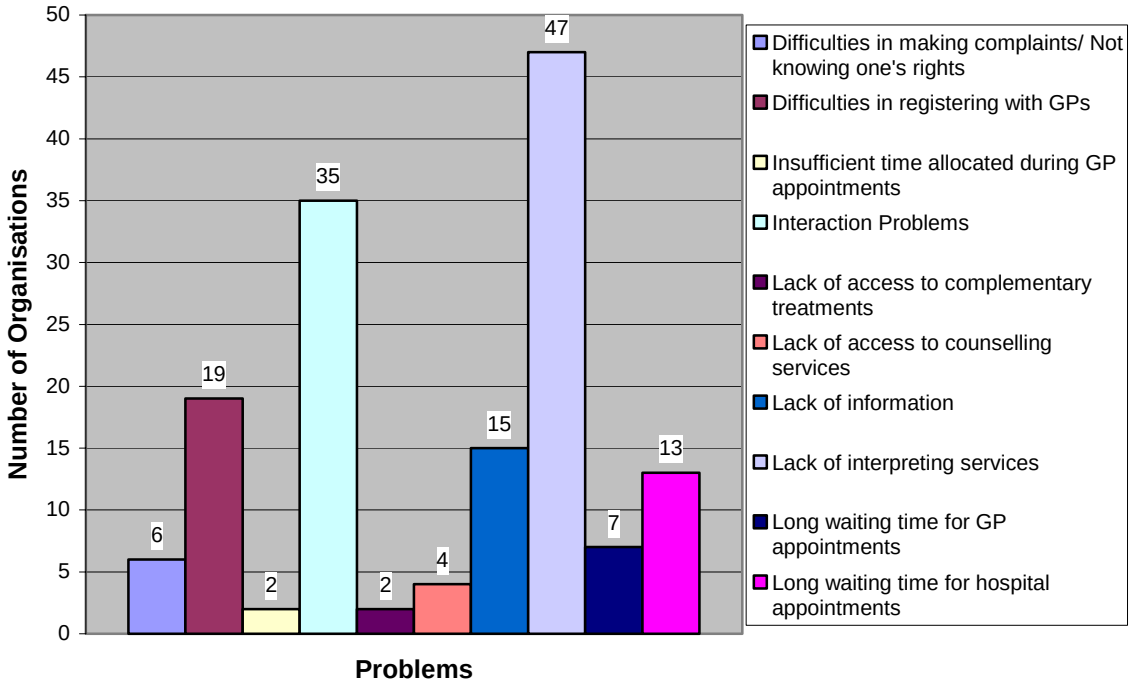
7. Health Concerns

This section covers those health issues which participant groups considered as major health concerns for them and members of their communities.

7.1 Accessing Health Services

Problems about accessing health services were mentioned by 110 organisations (55%). Accessing health services is the single most important health concern reported by community organisations. It is far more pressing than concerns about particular illnesses or conditions, the most important of which (problems around mental health and well-being) were mentioned by 68 organisations (34%). This finding matches our information on health projects which showed that access to health services was the second most likely topic about which organisations providing information and running projects even though such activities are unlikely to receive funding. (See section 4, p. 16)

Figure 7: Problems with Accessing Services



The majority of reported access problems (in particular, interpreting, and interaction) were related to GP services rather than hospital staff. However, because in a number of instances organisations were vague about whether a particular problem related to GPs or hospitals it was considered better to group issues together in terms of type rather than the service.

Interpreting

Lack of interpreting services was the single most important access issue. One organisation described the problem as follows:

"The key issue for the community is about interpreting services from GPs. We are concerned that GPs are still not asking their patients if they need interpreting services. As a result, many clients look for Arabic speaking GPs …".

A Latin-American organisation also mentioned that clients looked around for Latin American doctors, while a Chinese organisation and a Sikh temple organise consultations for their clients with doctors from their own community. Clearly this is not a solution open to the majority of BME groups. (See section 4.3 on treatment in the community, p. 20).

Interaction
The second most important issue was personal interaction. Most organisations mentioned interaction difficulties with GPs but some also mentioned similar difficulties with receptionists and hospital staff.

Interaction difficulties centred around two themes: Firstly, there is a lack of faith in the clinical effectiveness of GP consultations resulting from a perception that GPs do not take symptoms reported by BME patients seriously and therefore do not prescribe appropriate medication or refer them to specialist services early enough. Secondly, there is a perception that doctors do not treat BME patients with appropriate respect, sympathy and understanding.

According to a Chinese organisation many of their clients simply don't have confidence in the British health system. An Afghan organisation complained that GPs and hospital staff stereotyped their clients and downplayed their symptoms without investigating the causes. Similar perceptions were reported by several other organisations that complained that GPs do not properly listen to patients, make light of their symptoms, are reluctant to prescribe anything but painkillers and do not refer them to specialist services until their illness has significantly worsened.

One African organisation described GPs as ***"unsympathetic"***, while another African organisation specialising in patients with HIV said that their clients felt ***"misunderstood by GPs"***. A black mental health charity said the problem was so bad that their clients simply refuse to attend GP surgeries. A number of organisations complained that services were culturally insensitive or inappropriate. Several Arabic and Bangladeshi organisations as well as organisations working with people with HIV identified racist or at least discriminatory behaviour from medical staff as a major health concern. A Latin American organisation reported a lack of engagement from GPs stating that their clients ***"complain that doctors just give them a tablet and send them away"***.

An African organisation summed up the problem as follows: ***"not being respected, casual and over-hasty treatment, complaints not considered but dismissed out of hand, not being appropriately referred to specialist services".***

Registration
The third most significant problem identified was registering with GPs. The two issues here appear to be information and immigration status. The majority of organisations which mentioned problems about registration said that their clients lacked the information about how to register. An Eritrean organisation mentioned that clients were not always sure about their entitlement and an Angolan organisation said that their clients were being refused registration. Several organisations and faith groups, mentioned that their clients were unable to register with GPs because of their immigration status.

Appointments
Several organisations mentioned problems with the length of time it takes to have a GP or hospital appointment and the time allocated during appointments. However, these were mentioned by far fewer organisations than the other problems mentioned previously. It is likely that these issues were not omitted by the majority of the organisations because they are unimportant but because they are not perceived to affect BME communities disproportionately. In other words, BME groups accept that everyone has to wait a long time for an appointment and that is seen as a genuine issue of scarce resources rather than a question of discrimination.

Conclusions from this section:
Access to services, GP practices in particular, remains the most significant health issue for BME communities and a major contributor to health inequalities. Arguably, the persistence of this issue over so many years indicates a fundamental flaw in the way PCTs have dealt with it so far. The steady increase in spending on interpreting and translation services in KCW over the last few years has been necessary, important and welcome. However, overcoming the language barrier cannot

be dealt with in isolation of all aspects of access to services, i.e. interaction with GPs and registration. The fact that access is still a major health issue to so many BME organisations shows that without adopting a holistic approach to this issue, real change will remain out of reach.

A recent study on the experience of Bangladeshi people in accessing diabetes services has also found that initial access to services does not necessarily ensure appropriate health care or that needs will be met. The authors write that: *"…conventional analysis of access it terms of barriers to be overcome misses a crucial dimension: the ability to make full use of the service. Gaining access does not mean that needs will be met appropriately, and patients vary in the extent to which they are able and enabled to play an active role in obtaining the services they need."* (Rhodes *et al*, 2003, p. 171). They conclude that: *"Access entails not simply entry into a service but the opportunity to take full advantage of it."* (Rhodes *et al*, 2003, p. 182). Improving access therefore, must be assessed more broadly in terms of meeting needs rather than just overcoming initial barriers. Empowering communities, working in partnership with them and enabling them to make use of the services available to them are crucial dimensions to meeting those needs.

Furthermore, this study has underlined that problems in accessing services cannot be attributed solely to cultural differences of a specific ethnic group but rather cut across various ethnic groups and reflect gaps in service provision. Rhodes *et al* also argue that: *"The specific difficulties experienced by the Bangladeshi patients, in particular in terms of language barriers, intensified their vulnerability to, and thus highlighted, general weaknesses in provision. However, the boarder range of similarities with other groups suggest that, rather than focusing exclusively on a need for culturally sensitive services for culturally distinctive groups, there is a need to consider dimensions of access which cut across ethnic divisions."* (Rhodes *et al*, 2003, pp. 185-186).

Concerns about access to health care for BME communities have also been raised in a recent King's Fund briefing which stated: *"There is some evidence that the NHS has not catered well to Britain's 'diverse' population."* (Access to healthcare for minority ethnic groups, 2006, p. 3). This briefing also highlights the need for better data collection so that access to services can be monitored. The authors state that: *"The evidence base for more systematic investigation of any inequities in access to care has been hampered by the failure of NHS institutions to collect ethnicity data on patients both at hospital and primary care level."* (Access to healthcare for minority ethnic groups, 2006, p. 3).

Therefore, the **main recommendations** from this section are:

- The focus of the PCTs and NHS Trusts should be on addressing the gaps and weaknesses in services. This should include raising awareness of access issues and training provision amongst health professionals, especially GPs, practice managers and receptionists. While, patient education and developing the BME communities' understanding of health provision is important and should be catered for, the focus must remain on the need to examine all aspects of access to ensure that needs are met.
- Ethnicity data: collection of ethnicity data at primary and secondary care levels is essential to understanding inequalities in access to health services.

7.2 Health conditions and lifestyles

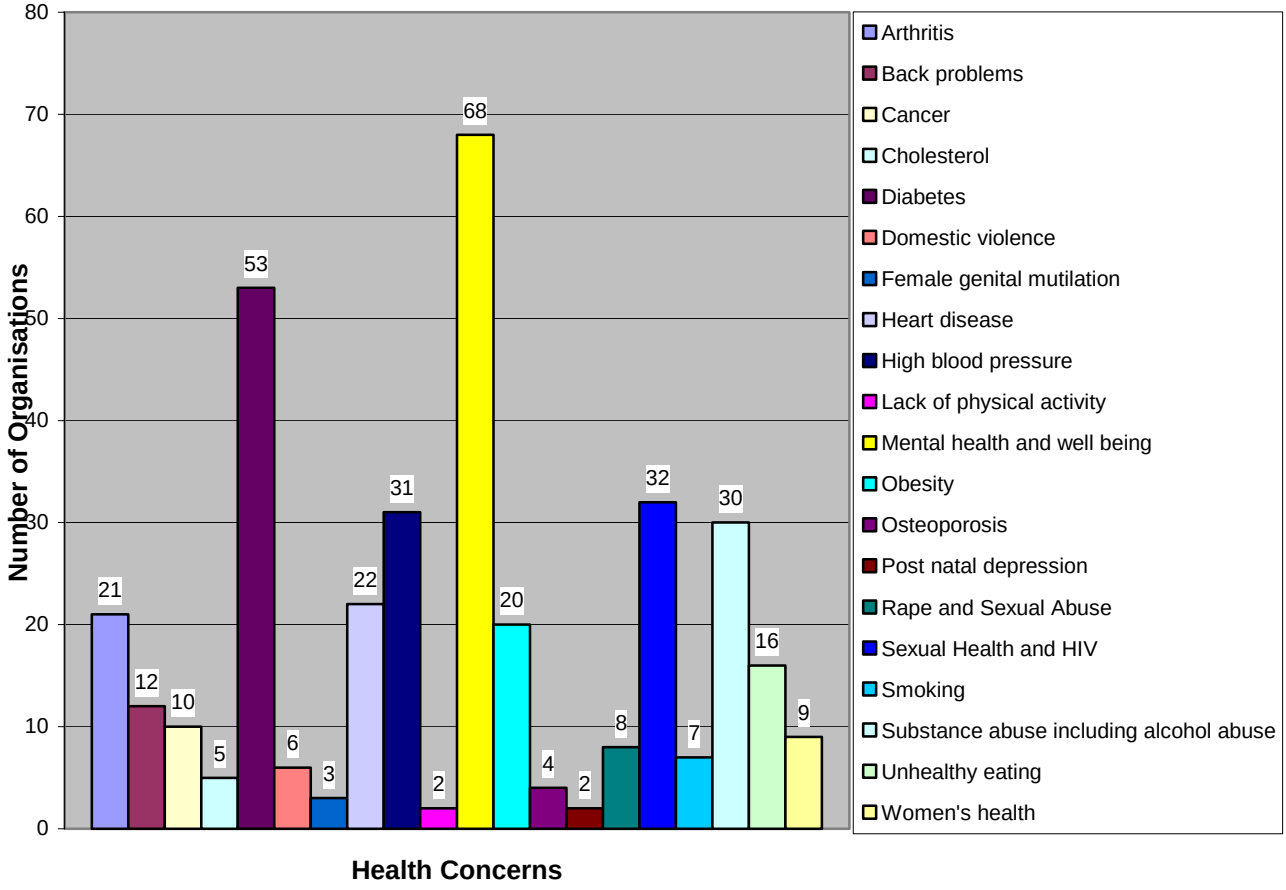
Mental health and wellbeing, particularly depression, stress and anxiety is the most pressing health concern in BME communities with regard to health conditions (mentioned by 68 organisations, 34%). Diabetes was also a major health concern (mentioned by 53 organisations (26.5%) followed by sexual health and HIV, high blood pressure and substance misuse (32 organisations, 16%; 31 organisations, 15.5%; 30 organisations, 15%). They are followed by heart disease, arthritis, obesity and unhealthy eating (22 organisations, 11%; 21 organisations, 10.5%; 20 organisations, 10%; 16 organisations, 8%). In contrast, lack of physical activities, and smoking do not appear to be major health concerns in the BME communities (2 organisations, 1%; 7 organisations, 3.5%).

Concerns about mental health and wellbeing were found across community organisations. Whenever specified, mental health concerns were about depression, stress, isolation, anxiety and loneliness. Psychotic illnesses were not mentioned by any organisation. Mental health and well-being issues may be more prevalent amongst asylum seekers and refugees and an African organisation which works with people with HIV suggested that depression and mental health problems were linked to immigration. However since the majority of organisations have a

proportion of clients who are asylum seekers or refugees, this is difficult to quantify. The finding that mental health and wellbeing is the biggest health concern in the community matches the previous finding (section 4.2, p.18; section 4.3, p.19) that mental health and wellbeing is the topic about which organisations are most likely to run a project.

Diabetes is clearly a major health concern for BME communities – and this finding is to be expected since Type 2 diabetes is more prevalent amongst BME communities (Health Survey for England 2004, pp. 7-8). Diabetes is a much greater concern than the associated issues of lack of physical activities, obesity and unhealthy eating although the later two did raise some concerns. Statistically, many BME communities are far less likely to take part in physical activity but are less likely to be obese, eat less fat and are more likely to eat five portions of fruit and vegetables, but also consume more salt than the general population (Health Survey for England 2004, pp. 13-14)[6]. In terms of our previous findings (section 4.1, pp. 16-17; section 4.2, pp. 18) we have found that there are plenty of activities around healthy eating and physical activity.

Figure 8: Health Concerns in the Community



Sexual health and HIV concerns were mentioned mainly by African and mainstream charities but also by Latin American faith groups and one Arab and one Bengali Women's organisations. The level of concern seems to fairly evenly matched with the activities around sexual health.

High blood pressure is a significant health concern for BME communities, considerably higher than concern for heart disease or other associated risks such as cholesterol, smoking, obesity, unhealthy eating or lack of physical activity. Statistically, BME communities have slightly higher blood pressure than the general population (Health Survey for England 2004, p. 13).

It is significant that a number of organisations including a number of faith organisations mentioned concerns around domestic violence, rape and sexual abuse. It is one of the advantages of using open ended questions that such information can be elicited. It is very likely that many more organisations would have mentioned these issues had there been a specific question on this topic.

[6] The figures used here are very general –there are important differences between particular ethnic groups and between men and women.

It is interesting that cancer and heart disease were mentioned by so few organisations as major health concerns. This might be because they are not seen as issues which affect BME communities in particular or because they are not seen as preventable and therefore viewed fatalistically.

The conclusions and recommendations from this section:

- Mental health: The fact that a large number of BME organisations are concerned about mental health and wellbeing underlines unmet needs and gaps in service provision in KCW. This issue and the recommendations about how to respond to it were the subject of the Forum's previous report (2004/05) "Caught Between Stigma & Inequality".
- Diabetes: it is a major health issue for many BME communities. Therefore, developing services for the treatment and management of diabetes in the community is necessary to meet this need. Therefore, the new diabetes centre at 4 Maida Vale is a welcome opportunity for BME groups to have better access to diabetes services, and equally for the PCT to build on the existing resources and strengths within these groups in terms of provision of diabetes education and advice, through forging effective partnerships with these groups.
- In addition, this research has identified other major health concerns for BME organisations in KCW, including blood pressure and heart disease, substance misuse, obesity and others. This data will enable the PCTs and NHS Trusts to identify community groups in order to work with them to ensure that services are available to them.

8. Unregulated Migrants

During the course of this project, our search for new BME groups led us to believe that there is a sizeable unregulated migrant community in the Kensington & Chelsea and Westminster area. This population includes failed asylum seekers, overstayers, and others who are in breach of UK immigration regulations. Although it has not been possible to identify the size of this group or the ethnicities it comprises, our research indicates that it is a substantial population.

During our research, our volunteers identified that many organisations and churches provide a wide range of health related services that would normally be provided by the NHS, to unregulated migrants. These services include:

- Counselling and support for mental wellbeing issues, including depression, anxiety and stress often related to immigration problems.
- Support in accessing services, including interpreting.
- Support in dealing with alcohol and substance misuse problems.
- Information and advice on various health conditions such as diabetes, obesity, back pain, high blood pressure, domestic violence, and family & children issues.

Furthermore, the groups and organisations including churches that provide services for unregulated migrants, mentioned the very serious distress that unregulated migrants suffer which is related to immigration problems and the associated lack of access to NHS services. The priests and community leaders who work closely with this group have expressed concerns about this humanitarian problem and the urgent need to deal with it. Many talked about the difficulties they faced in coping with these issues without having received any training or funding relevant to this work, although they remain steadfast in their commitment to continue providing services for this group.

Conclusions and recommendations from this section:

This humanitarian issue needs to be addressed. Furthermore, from a pragmatic perspective, the lack of access to primary care services faced by unregulated migrants inevitably increases pressure on A&E and hospitals, because minor health problems that could be easily and cheaply dealt with at primary care level are allowed to develop into emergencies. Currently, the government accepts that unregulated migrants are entitled to emergency health care on a humanitarian basis but has limited their access to primary care – which undermines other efforts to make NHS services seamless and promote community based services. It is clear, that this situation cannot be

allowed to continue and that the DH need to ensure that this group, who contributes substantially to our economy without any recourse to public funds, have full access to NHS services. The current situation, not only breaches the basic human rights of unregulated migrants, it is inequitable, expensive and inefficient.

Next Steps

To take this report forward and to address the findings of this project, the BME Health Forum will be working on two levels: firstly it will work with K&C and Westminster PCTs and NHS Trusts in KCW. This involves working with the PCTs, GPs and stakeholders in order to develop policies and structures to address the health needs of BME communities and to ensure that these communities are properly involved in the planning and commissioning of health care in the area.

Secondly, it will develop projects and task groups to address some of the findings of this project. For example, the concern about access to GPs, which is one of the main findings of the report, will be addressed by a project that will be developed by the Forum to improve access to GP services for people from BME communities. The project will be developed in partnership with key stakeholders, including representatives from BME groups, voluntary sector, PCTs and GP practices.

Moreover, the Forum recognises that it has not been able to reach out to and involve some BME communities due to lack of capacity. Therefore, we have identified "involving new communities in our work" as one of our priorities for the next year and efforts will be made to engage with those who have not been involved in the past.

The Forum will also work with the PCTs and key stakeholders to develop a strategy for achieving wider participation of BME organisations in public consultation on health issues and in health related activities.

For more information about this report and how its findings will be taken forward, please contact the BME Health Forum at:

BME Health Forum
c/o Westminster PCT, 15 Marylebone Road, London NW1 5JD
Tel: 020 7150 8128, fax: 020 7150 8105
E-mail: bmehealthforum@westminster-pct.nhs.uk
Website: www.westminster-pct.nhs.uk/diversity/bmehealthforum.htm

Bibliography:

Access to healthcare for minority ethnic groups (2006) King's Fund, pp. 1-5.
http://www.kingsfund.org.uk/resources/briefings/access_to_health.html

Rhodes, P., Nocon, A. & Wright J. (2003) Access to Diabetes Services: The Experience of Bangladeshi People in Bradford, UK, *Ethnicity & Health; 8(3): 171-188.*

Sproston K. & Mindell J. (2004) *Health Survey for England: The Health of Minority Ethnic Groups.* London: Health and Social Care Information Centre.
http://www.ic.nhs.uk/pubs/healthsurvey2004ethnicfull

Appendix A

The volunteers who carried out the interviews

(This list includes only those who completed the training and participated in the project)

Name	Group/organisation
Abdi Ismail	East African Society
Abu Hamza	Queens Park Bangladeshi Association
Ali Abubaker	Volunteer Centre Westminster
Amal Ossman	London Care Connections
Anne-Cécile Maffat	Arab Women Centre
*Aranos Teclehaimanot	Fifty Plus Eritrean Welfare Association
Awad Abdel Salam	Westminster Befriend a Family
Dedah Adu	Organisation for Advancement of African Women (ORGAAW)
Flaminia Ferrari	Migrant Resource Centre
Floresse Lembe	Congolese Centre for Information & Advice
Lillian Grant	Umoja Pamoja
Margarita Henao	Abbey Community Centre
Mary Babirye	Umoja Pamoja
Meletetsega Aranos	Fifty Plus Eritrean Welfare Association
Mengestab Mindal	Volunteer Centre Westminster
Nurianie Salaam	Westminster Befriend a Family
Sara Al Shawish	British Iraqi Centre
Thembi Cynthia Mbambo	Pamodzi
Wei-Yee Kung	Chinese National Healthy Living Centre
Yakub Mohammed	Volunteer Centre Westminster

** Mr Teclehaimanot passed away during the project*

Appendix B

The BME Health Forum

Research into the participation of BME groups and organisations in health consultations and activities in K&C and Westminster

Interview Questionnaire

Section A: about the organisation/group

1. Name of interviewee: _____
2. Job title of interviewee: _____
3. Name of organisation or group: _____
4. Address: _____

   _____ Post Code: _____

   Tel No: _____ Fax No: _____

   E-mail: _____ Website: _____
5. What does your organisation do? _____

   _____

   _____
6. What community/communities do you serve? _____

   Is this based on (please tick one or more): □ Ethnic background □ Nationality □ National origin □ Faith □ Political affiliation □ Gender □ Other (please specify) _____

   _____
7. Status – is the organisation/group (please tick one or more):
   □ A registered charity □ A company limited by guarantee □ An informal group □ A sub-group of another group (please specify) _____
8. What year was your organisation formed? _____
9. Have you asked for help or support from statutory agencies? □ Yes □ No

   If your answer to question 9 was yes:

   9.1 What kind of support have you asked for (please tick): □ Funds □ Advice □ Promotional materials □ Training □ speakers □ Other (please specify) _____

   9.2 Did you receive the support you sought? _____

Section B: involvement in health activities

10. Are any of your activities aimed at addressing health issues? □ Yes □ No □ Sometimes

If the answer to the above question was 'Yes' or 'Sometimes':

10.1 Can you tell us more about this?

10.2 What led your group to become involved with health issues?

10.3 What kind of health-related issues do your members raise with you? Are these the key health issues for your community? (This includes access to health services such as GPs, hospitals, etc and commonly occurring illnesses within the community)

11. Would you like to be involved in running more health-related activities in your organisation? □ Yes □ No.

11.1 If yes, can you describe the type of activities you would like to develop?

11.2 What, if any, do you think are the barriers that are stopping your organisation from becoming more involved in health projects/activities?

12. Have you participated in any health-related public consultation organised by a hospital or a Primary Care Trust? □ Yes □ No
13. If 'Yes':

13.1 What was it about? _____

13.2 When did it take place? _____

13.3 Can you comment on how useful you felt it was? _____

_____

If 'No', why is that? (Please select one or more of the following):

☐ Lack of information about such consultations
☐ Lack of resources
☐ Health is not a priority for us at this stage
☐ Other reasons – please specify _____

14. Have you participated in any of the BME Health Forum's activities or projects in the past?
☐ Yes ☐ No

If 'Yes', can you please tell us what made you participate?

If 'No', why is that? (Please select one or more of the following):

☐ Lack of information about the Forum and its activities
☐ We cannot see the benefits of getting involved in a policy Forum
☐ Lack of resources
☐ Health is not a priority for us at this stage
☐ Other reasons – please specify _____

15. Would you like to attend future Forum meetings/events?

☐ Yes ☐ No

16. Do you know about any small groups or organisations that are not involved in health consultations and activities? ☐ Yes ☐ No

If 'Yes', please give us their contact details.

17. Do you have any questions for us?

Thank you for your time

Please return this questionnaire to:
BME Health Forum, c/o Westminster PCT, 15 Marylebone Road, London NW1 5JD
Tel: 020 7150 8128, Fax: 020 7150 8105, amjad.taha@westminster-pct.nhs.uk

Appendix C

Names of the organisations interviewed

A Moveable Feast
Abbey Community Centre
Abundance Arts
Advocate for Mental Health
Afghan Dosti Society (ADS)
African Caribbean Elders
African People's Link (APL)
African Womens Group
Agape Christian Centre
Al Madina Nursery School
Al Noor Youth Association
Al-Awda Trust
Albahdja
Al-Hasaniya Moroccan Women's Centre
Anglo Czech Slocak Welfare Association
Angolan Community
An-Najaat project
Arabic Family Service / Parkside Clinic
Arabic speaking information and advice centre
Arab Women's Centre
Arab Women's voice
Asian Family Services
Asian Muslim Women's Association (AMWA)
Bangladesh Centre
Bayswater Families Centre
Bayswater Social and Cultural Association
Bengali Group (Soho Family Centre)
Bengali Institute
Bengali Women's Group
Bengali Women's Network (BWN)
Bishop Ho Ming Wah Association
Black and Ethnic Minority Diabetes Association
Black Disabled People's Association
Black Unity Forum
Blin Community
Blin Language and Culture
BME Residence Group
Bosnia Herzegovina Community UK
Bosnian Supplementary School
British Arabs Resource Centre
Buddha Light International Association (BLIA)
Camden & Westminster RTP
Central African Help Centre
Central Gurdwara
Central London Youth Development Trust
Centre for Filipinos
Centro Cristiano - Casa de Adorores
Chelsea Asian Women's Group
Chelsea Methodist Church, Narthex Pastoral Centre
Children and Victims of Poverty International
Chinese Community Centre
Chinese National Healthy Living Centre
Cluster Branches Ministry
Community of Christ in London
Comunidad Cristiana De Londres

Confederation of African Organisations
Connexions (Westminster)
Dadihiye Development Organisation
Dalgarno Supplementary School
Debanma heritage Forum
Depaul Trust New to London
Diamond Life
Earls Court Community Project
East African Society
Ebony Steelband Trust
Egyptian Community Association
Egyptian Community Centre
Egyptian Association
Emanuel Evangelical Church
Eritrean Community Support
Eritrean Cultural Support Group in UK
Eritrean Elders Association
Eritrean Muslim Community Association.
Eritrean Parents and Children Association
Ethiopean Women Empowerement Group
Ethipean Refugee Association
Faik Coniga
Family Service Unit, Queens Park
Family Support Group
Forum of Faith
Gambian Mandigo society
Genuine Empowerement of mothers in society
Ginagi Foundation
Harambee Development Group
Havengrove
Horn Reflections Ltd
Hungerford Drug Project
India Welfare Society
Iraqi British Centre
Islamic Cultural Centre & Mosque
Ivorian Advice and Support Group
Jesus is Lord
Jewish Council For Racial Equality
Kalayaan
Kensington & Chelsea Advocacy Alliance
Kensington & Chelsea Africans Commonwealth Association (KCACA)
Kensington Asian Women's Association
Kensington Temple/ Portuguese Group
Kongolese Centre for information & Advice
Kono Women
Kulan Somali Organisation
Kung Ho Association
Kurdish Exile Association
Kyu-yo-bu-shin
Latin American Elderly Project
Latin Front
Latin-American Community Assoc (Latca)
Light ling community association
Lighthouse West London - African Department
London Care Connections
London Kensington Moroccan Widadia
London Tigers
Marylebone Bangladeshi Society
MCWG
Metropole College

Migrant and Refugee Communities Forum (MRCF)
Migrants Resource Centre
Moroccan Supplementary School
Muslim Cultural Heritage Centre
National Coalition for black volunteering
Naz Project London
New Citizens Voice
New Roots (Rubgy House)
North West London Angolan Association
North Westminster Community School
Notre Dame Refugee Centre
Nubian Mothers Group
Olabisi Olaleye Foundation
Organisation for the Advancement of African Women (ORGAAW)
Over 55 Well Being Project
Pad De Vida Apostolic Ministries
Pae-Ben Women's Association
Pamodzi
Partnership for Supplementary Schools
Persian Care Centre
Photoworks Westminster
Pimento
Prospect Kensington Ltd
Queens Park Bangaldeshi Association
Queens Park New Media Centre
Race Equality Partnership Kensington & Chelsea
Rain Trust
Refugee and Asylum Project Coordinator
Relief Society for Poles Trust
Response Community Projects
Salon del Reino
Seicho -No-Ie
Serbian Community Centre
Sharp: The Chemical Dependency Centre
Sierre Leone Youth Association
Sixty Plus
Soho Family Centre
Soho Family Centre Chinese Group
Somali Advisory Bureau
Somali Mother & Childrens Organisation
Space KC
Spanish Portuguese Speakers Elderly Group
Spanish/Portuguese Speakers Parents Group
St Anthonio Eritrean Refugee Women's Group
Sudan People's Support Association
Sudanese Supplamentary School
Sudanese Women's Rights Group
Takullo Community Centre
The Afiya Trust
The Anglo-Egyptian Society
The Arabic Speakers Development Organisation
The Avenue's Youth Project
The Cardinal Hume Centre
The Consortium Of Bengali Associations
The first Georgian Supplementary School in the UK
The Latin-American Golden Years Day Centre
The Mother's Bridge of Love (MBL)
The Passage
The Pepperpot Day Centre
Uganda Aids Action Fund

UK Coalition of People Living with HIV and AIDS
Umoja Pamoja
Unitarian Church
VCW Refugee Project
Victim Support, K&C
WECH Community Centre
West London Moroccan Widadia
West North West London Vietnamese Association
Westbourne Park Baptist Church
Westbourne Park Family Centre
Westminster Advocacy Service
Westminster Algerian Welfare Society
Westminster Bangladeshi Association (WBA)
Westminster Befriend a Family
Westminster Drug Project
Westminster Mind (Flexicare)
Westminster Partnership for Race Equality (WRPE)
Westminster Refugee Consortium
Wings of Hope Community Association
WSPM Agape Community Project
Yaa Asantewaa Arts & Community Centre
Yika-Samba (Caphaa)
You Are Not Alone (YANA)
Youth Project International
Zivko Firfoy Folklore Group

In due course, the BME Health Forum will be producing and publishing a directory of these organisations, their contact details and a brief description of what they do.

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