Good Access in Practice

Promoting community development in the delivery of healthcare
“Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.”

Article 25, Universal Declaration of Human Rights, 1946
The Black and Minority Ethnic (BME) Health Forum would like to thank Al-Hasaniya Moroccan Women's Centre, the Chinese National Healthy Living Centre, Midaye Somali Development Network, Queens Park Bangladesh Association and WSPM Agape Community Project, for their commitment and for sharing their experience and knowledge of the communities they serve, without which this programme would not have been successful.

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This report was written by Isis Amlak.
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The Good Practices for Access & Wellbeing Programme (GPAW)

Executive Summary and Recommendations

1. Introduction

This report describes the findings of the Good Practices for Access and Wellbeing Programme (GPAW). GPAW was an eighteen month programme funded by NHS Kensington and Chelsea and NHS Westminster. It complements and develops further the BME Health Forum’s previous work on access to primary care and was designed to demonstrate practical measures which would improve access to primary care health services for people from Black and Minority Ethnic (BME) communities in the two boroughs.

The report identifies a number of key successes and challenges in delivering this programme. It makes recommendations about what commissioners, providers and community organisations can do to improve the experience of healthcare for BME residents.

2. Key Findings

The baseline assessment undertaken at the start of the programme confirmed that a significant number of BME service users continue to face barriers to equal access to health services. They are dissatisfied with mainstream services which they perceive as lacking in understanding and consideration. This situation can result in poorer health compared to other groups, with unnecessary visits to Accident and Emergency Units, higher rates of hospital admission, and the likelihood of more complex, intrusive interventions at a higher cost.

The Programme’s findings about these barriers, and how best to reduce or remove them, cover two areas:

2.1 User Experience

2.1.1. Awareness of Services

Some key findings from the Independent Evaluation were:

- At the beginning of the project, 325 community members were interviewed about their understanding and use of health services. From those who said they needed support from an interpreter to communicate with health professionals, only 86% actually used interpreters. Furthermore, half the interpreters used were informal (friends and family) rather than formal.

1 Described in ‘Primary Concern’, BME Health Forum, June 2008.
Among the people who did not use an interpreter, only half knew that they were entitled to use a formal interpreter.2

At the end of the project, when community members were interviewed again, 63% of people who had used an interpreter had used a formal interpreter. Furthermore, from the people who were still not using interpreters, 59% knew they were entitled to use a formal interpreter.

There was a similar increase in awareness of other services in terms of location and appropriate use. In particular, 63% of users reported that the project made them more aware of NHS services and 53% of users reported that as a result of the project their confidence increased.3

These findings suggest a modest but important improvement in the understanding and well being of community members. To improve these further, the Programme developed:

- An Interpreting Guide for communities which was complemented by an Interpreting Guide for staff produced by NHS Westminster. Both guides were distributed to community organisations, GP practices and dental practices.
- Fact Cards explaining NHS Services in six community languages which were distributed to community organisations.

2.1.2 Case Studies, Cultural Brokerage and Health Information

The one-to-one work between the Access Facilitators and the clients demonstrates that there are still considerable difficulties between a significant number of BME patients and clinicians caused by mutual misunderstandings. The Access Facilitators were able to resolve some of these problems by a variety of methods, including providing information, making appropriate appointments, requesting interpreters, completing forms and generally negotiating and advocating on behalf of patients. This service was very successful as 94% of respondents reported that they received help to resolve an issue they had with the health service.

The success of this work supports the use of cultural brokerage, (refer to page 14). The Access Facilitators were successful in their work because they were able to negotiate between two cultural systems – their community and the NHS.

The Access Facilitators also ensured that clients were not just passive recipients of help but were given the tools and information to advocate for themselves whenever possible.

2 'Evaluation of the Shared Leadership (BME) Scheme for Kensington & Chelsea and Westminster BME Health Forum', Shared Intelligence, November 2009

3 'Evaluation of the Good Practices for Access and Well Being Project', Shared Intelligence, May 2010
To support this empowerment approach, clients attended ESOL for Health and Health Information sessions which increased their understanding of the health service and enabled them to gain a better understanding of health terminology.

2.2 Organisational Barriers

The GPAW Programme was successful in working with local BME community groups

- To support and empower BME service users;
- To develop accessible information materials in community languages; and
- To develop good practice guidance.

This success is evidenced by the independent evaluation completed by Shared Intelligence, by the outputs of the Programme, and by the satisfaction of participants and service users. GPAW demonstrated the value of using a community development approach to transform the dynamic between service users and the healthcare system. This enabled the participant community organisations to systematically identify the focus for their activity and to target the content of the interpreting guides and fact cards effectively within their communities.

Nevertheless, while all participant community organisations received the same level of resources and support, some were more successful in delivering the programme than others. This points to some key considerations for effective community development work:

- Recognising the existing skill level of individual participants;
- Recognising the capacity and expertise of participant community organisations;
- Providing an appropriate level of resources (funding and developmental support) to address the above.

While engagement with community organisations was highly effective, this was not complemented by a significant level of engagement with Primary Care Practices. An analysis of the reasons for this contrasting experience suggests two key factors:

- *At the early stages of the programme, it was unclear to Practices what the key deliverables of the programme would be.* Therefore, the benefits of involvement remained unclear. As the programme progressed, and outcomes were delivered, this has now been addressed;

- *The capacity of Practices to engage in activity outside of individual patient care is severely limited.* Though a number of Practices expressed support for the Programme and a willingness to participate more actively, this proved difficult.

The timing of the GPAW programme was especially challenging due to the ongoing Swine Flu Pandemic. However, even in more favourable circumstances, active participation of GP practices would have proven difficult, despite the fact that there was agreement that this was desirable.

This is because there are multiple structural barriers to the involvement of GP practices in activity which is not focused on individual clinical performance.

3. Conclusions

Action to reduce barriers to effective communication remains key to improving the health experience of BME communities and addressing persistent health inequalities. Interpreting provision needs to be of high quality, better regulated, and more widely disseminated to service providers and communities. There needs to be a greater emphasis on health education in culturally appropriate and user friendly formats. BME communities need to learn the language of health which will empower them to communicate to speak up about their conditions.

Additionally, our experience of the successes and shortcomings of the programme leads to a core set of recommendations for a significant change to the way that primary care services are commissioned. Such change will lead to effective engagement and produce sustainable and long term improvement.

We strongly recommend the adoption of a community development based approach to underpin the governance and management of primary health care services, following the Community Health Centre (CHC) model which has been in operation in Canada for more than thirty years and has proven success.5

CHCs are voluntary organisations that offer local people a number of services, including health services, and are specifically aimed at communities that face barriers in accessing primary care. CHCs are multi-disciplinary so that:

"they support clients not only by providing clinical services but also by dealing with the social, environmental and economic determinants of health...are community led, accessible ...and work under explicit anti-oppression policies ..."6

Adopting a sustainable cultural brokerage model, (refer to page 14), alongside the CHC model of governance will provide a solution to the barriers experienced by BME groups. For example:

- Such a model will facilitate cultural change amongst both service providers and recipients;
- It will enable communities themselves to inform the provision of health services based on their unique ability to understand their own health needs;

6 I bid
• It will enable BME communities to learn the language of health and to empower them to communicate effectively about their needs;

• It will also enable providers to understand the context, culture and values in which their service users function, in order to provide effective care.

4. Recommendations

These recommendations are complemented by the recommendations of the independent evaluation, which are also listed in Appendix 3.

Recommendation 1

All stakeholders should work together to implement a model for the governance of primary care services which is based on the Canadian Community Health Centre (CHC). This should, in the first instance, be led by the Primary Care Trusts (PCTs) and Practice Based Commissioning Groups (PBC) in the context of their programmes for the development of community based services.

Recommendation 2

In addition to developing a Community Health Centre (CHC) model commissioners should ensure BME communities are actively involved in all service developments, at all stages from inception to evaluation. This will help demonstrate World Class Commissioning competencies and meet Public and Patient Involvement requirements and Equalities Duties.

Recommendation 3

Stakeholders should use a community development approach for engagement with BME communities, (refer to page 13). This will include providing appropriate resources for:

• dialogue with community organisations, particularly around difficult to engage issues;

• Dissemination of key health messages;

• Close partnership with community organisations in the delivery of preventative services, including screening services and procedures;

• Recognising the importance of actively engaging children and young people as key stakeholders in promoting good practice.
Recommendation 4

Commissioners should adopt a cultural brokerage approach (refer to page 14) and support community organisations to develop the skills and capacity required to deliver this effectively.

Recommendation 5

BME Access Facilitators should be recruited and co-located in GP surgeries and community organisations with the remit to educate and support communities and health professionals. This will facilitate greater access, improve communication and increase understanding.

Recommendation 6

To ensure BME communities and health professionals continue to benefit from the output of the GPAW project, there needs to be:

- A commitment from the two PCTs and other key stakeholders to reprint, disseminate and embed use of the interpreting guides and fact cards;
- A commitment to produce the GPAW literature in other community languages, in addition to the six included in the programme.

Recommendation 7

Based on the success of the existing course, ESOL for health should be continued and extended to improve health literacy. This model needs further development to spread and sustain good practice.

Recommendation 8

Commissioners and the BME Health Forum should work in partnership to develop a training package for commissioners and providers. Training should focus on how best to support and develop community organisations in addressing barriers to health access and resulting health inequalities. This package should incorporate:

- The barriers to equitable access;
- The link between barriers to access and health inequalities;
- Best practice in the approach to supporting community organisations to address these barriers;
- The role of cultural brokerage in reducing barriers.
Recommendation 9

Second tier community and voluntary organisations should be funded to provide additional infrastructure support to BME communities and community voluntary organisations, in order to work in collaboration and promote partnership to address shared health and social issues. This will support community cohesion and increase the capacity of groups who often have a common purpose. There would also be a less burdensome transactional cost involved if community groups could work as a consortium when submitting funding applications in the current uncertain economic climate.
Introduction

The Good Practices for Access and Wellbeing (GPAW) programme is the result of ongoing work undertaken by the Black and Minority Ethnic (BME) Health Forum to address access to primary care for BME groups. This work began with the publication of the 2006 Report: ‘Minding the gaps - Are BME groups partners or substitutes in health provision?’, which identified that accessing GP practices was a major health concern for the majority of BME groups. The report identified that problems with access faced by BME communities in Kensington & Chelsea and Westminster (KCW) included lack of adequate interpreting, poor interaction between patients and GPs and barriers in registering with GPs.

This process entered its next chapter with the implementation of the two staged ‘Access to GP Practices’ project that was initiated with a process of research and investigation. This first part involved interviewing patients and health professionals, in order to identify the key issues. The outcome was ‘Primary Concern’, published in June 2008. This report’s key recommendations suggested that:

- The PCTs should ensure that they commission primary care services which are flexible and responsive to the needs of all groups. They should also commission community groups and the BME Health Forum to develop projects to improve access;

- GP Practices should use patient groups/panels, local community groups and the BME Health Forum as a route for improving their understanding of local communities and communities’ understanding of NHS services and practices;

- The BME Health Forum should work with practices to identify and develop good practice in relation to providing interpreting support;

- The BME Health Forum and community groups should actively promote the availability of interpreting services to their members.

The second stage of this project, which is documented here, has been about implementing these findings.

Methodology

Good Practices for Access & Wellbeing Programme Structure

GPAW started in April 2009 and finished in April 2010. It was funded by NHS Kensington and Chelsea and NHS Westminster. It was delivered by six community projects who were appointed through an open tender process.
The six organisations selected were:

- **Al-Hasaniya**: serving the needs of Moroccan and Arabic speaking women and their families;
- **Chinese National Healthy Living Centre**: promoting healthy living and access to health services for the Chinese community;
- **The Kongozeman Centre for Information and Advice**: providing a range of services to help African French and Lingala speakers;
- **Midaye Somali Development Network**: serving the needs of the Somali community and ethnic minorities;
- **Queens Park Bangladesh Association**: dedicated to the upliftment of Bangladeshi people in the Queens Park ward and the wider Bangladeshi communities in Westminster;
- **WSPM Agape**: supporting disadvantaged groups, including West African and Caribbean communities, residing in Westminster and Greater London.

### A Community Development Approach

The programme used a community development approach to support the pursuit of culturally and linguistically diverse services that meet the local need of BME communities.

*Community development involves changing the relationships between ordinary people and people in positions of power, so that everyone can take part in the issues that affect their lives. It starts from the principle that within any community there is a wealth of knowledge and experience which, if used in creative ways, can be channelled into collective action to achieve the communities' desired goals.*

*Community development practitioners work alongside people in communities to help build relationships with key people and organisations and to identify common concerns. They create opportunities for the community to learn new skills and, by enabling people to act together, community development practitioners help to foster social inclusion and equality.*

Through adopting this approach, the programme was able to enhance the capacity of community projects to deliver health care information, make referrals and provide advocacy, as required.

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Adopting a Cultural Brokerage Model of Health Delivery

Health systems are cultural systems. What an individual believes and understands as the root cause of an illness or medical condition is also culturally determined. The term “cultural broker” was first invented by anthropologists to explain their observation of mediation between cultures i.e. certain individuals acted as “go betweens”, or “negotiators on behalf of colonial governments and the societies they ruled”. Jezewski defined cultural brokering as “the act of bridging, linking or mediating between groups or persons of differing cultural backgrounds for the purpose of reducing conflict or producing change”.

Based on this definition, a cultural broker is a person or group who facilitates communication between different cultures. For this approach to work effectively, it is fundamental that cultural brokers have the trust and respect of the community with which they are working.

Adopting a Cultural Brokerage approach in health service delivery does not necessarily require that the cultural broker be a member of a particular cultural group or community. However, it is essential that s/he is knowledgeable about the health values, beliefs, and practices within the cultural group or community they serve.

S/he will need to have experience of the health care system and to have learned how to navigate it effectively for their community

Respecting diverse characteristics is essential in providing culturally competent services. A culturally competent service will be better placed to address the health inequalities faced by the community it serves. The cultural brokerage model respects self determination, self definition and cultural differences within communities; the principle being that communities determine their own needs.

Health Inequalities

It remains a disturbing fact that people from BME groups are amongst the most socially excluded. They suffer inequalities of health and consequently a poor quality of life.

*Fact: The prevalence of stroke among African Caribbean and South Asian men is 70% higher than the average.*

There is an over-representation of BME groups (42%) in mental health services compared with the overall population, particularly people from the African and Caribbean communities, Refugee men and Muslim women. BME groups account for 37% of the households in temporary accommodation accepted as vulnerable due to a mental health condition.


9 Race for Health - [www.raceforhealth.org](http://www.raceforhealth.org)
Despite an improvement in overall health in the UK over the last few decades, health inequalities within and between communities have continued to exist and in many cases have widened. BME communities are, ‘...more likely than others to live in deprived areas; be poor; be unemployed, compared with white people with similar qualifications; suffer ill-health and live in overcrowded and unpopular housing. They also experience widespread racial harassment and racist crime and are over-represented throughout the criminal justice system, from stop and search to prison’ (Social Exclusion Unit, 2003).10

Poverty and poor health go hand in hand; they impact upon people from all ethnic backgrounds in Britain and are linked to other forms of social deprivation. As people from some ethnic backgrounds tend to be disproportionately disadvantaged by social and economic deprivation, they also tend to suffer from worse health.

**Fact:** Infant mortality in England and Wales for children born to mothers from Pakistan is double the average.11

Overall there is compelling evidence that people from BME backgrounds are less successful in accessing health-related services and tend to experience poorer health. Life expectancy tends to be lower at all ages and for all causes of death.

### Key tasks for community projects

The key objectives for the community projects were to improve access to primary care services for their communities. This was to be achieved by working with patients and primary care providers to develop and disseminate good practice while increasing communities' knowledge of how to access and use those services. Objectives of the community projects were to:

- Identify members of BME communities experiencing barriers to accessing primary care services and engage them in this project;

- Develop a written guide on interpreting for patients, their families and their friends in order to ensure that community members are aware of the availability of official interpreting services and the risks of using unofficial interpreters;

- Produce a fact sheet for communities; and

- Produce a questionnaire in the top six community languages, to assess knowledge and use of health services.

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11 Race for Health—[www.raceforhealth.org](http://www.raceforhealth.org)
The Community projects were required to:
- Build their capacity to deliver health projects;
- Provide advocacy, information and signposting for members;
- Develop specialist knowledge and understanding of NHS services;
- Improve satisfaction of patients;
- Educate their communities and act as cultural brokers.

**GP Practices and Dentists**

The programme aimed to engage a number of GP and dental practices in KCW. The objective was to provide support to these primary care services to deal with cultural, language and communication issues with BME patients, including asylum seekers and refugees. In addition the programme aimed to:
- Reduce the length of clinical consultations at these services by working with BME patients on using clinical consultations effectively;
- Increase the list size of these practices by improving registration amongst the BME populations;
- Improve satisfaction levels amongst the patients of these primary care services by improving the satisfaction of an identified BME sample. This was to be monitored by measuring satisfaction of the sample at the beginning and end of the project. An anticipated outcome was a tried and tested model for monitoring patient satisfaction for BME communities, thus improving the patient experience;
- Work in partnership with these practices to review and adjust existing language support, communication and registration structures at these practices.

**The Programme Steering Group (PSG)**

The Programme Steering Group (PSG) was set up to provide advice on the implementation of the programme and guide the development of a programme of work. The group facilitated collaboration between the programme stakeholders: NHS Westminster, NHS Kensington & Chelsea, the BME Health Forum, community projects, the voluntary sector and patients. Individuals invited to join the group were expected to contribute their experience and knowledge in a positive manner for the life of the project.
The PSG provided strategic direction, guidance and support to the Forum manager, (who was also the programme manager), the programme coordinator and the community-based projects.

Access Facilitators

Each community project appointed an Access Facilitator whose responsibility was to deliver the programme of work. The roles of the Access Facilitators involved:

- **Advocacy**: to provide advocacy support to members/clients of the project to make their voices heard, to access services, to challenge or to raise complaints;
- **Information**: to provide information to the community with which they work, specifically around health;
- **Referrals**: to be able to make referrals to appropriate agencies and organizations;
- **Signposting**: to be able to signpost clients/members to where they can access the appropriate support, or services.

The role of the Access Facilitators was designed to improve the health of their communities by providing input to local health care providers and raising issues on behalf of their users, and by educating their communities on how to make effective use of services. The role supported users to make complaints or raise challenges and provided support to overcome cultural and language barriers.

The Project Delivery Group

A Project Delivery Group (PDG) was set up to facilitate partnership working across the six community projects in a flexible and productive manner. It enabled the coordinator to supervise and support the Access Facilitators to achieve the programme objectives as set out in Action Plan. The aims of the group were to:

- Facilitate well attended regular meetings;
- Work closely with the Programme Coordinator and other members of the management team as required;
- Share information on experiences of all aspects of project delivery;
- Channel the views, experiences and issues from community members into the programme;
- Coordinate advocacy, information, referral and signposting;
- Provide progress reports and examples of good practice to stakeholders;
- Represent the Community projects on the PSG and at other events and activities as required;
Membership of the delivery group formed part of the contract of employment for the Access Facilitators. A total of twenty two PDG sessions took place throughout the life of the Programme. Sessions were well attended, with no fewer than four Access Facilitators at any one session.

**Training, Development and Consultations**

Training and development were central to achieving the key objectives of the programme. Training needs assessments were completed at the outset and the project coordinator designed activities to improve, develop and build the Access Facilitators’ skills base, and their capacity to deliver the programme outputs.

All the training was well received by the Access Facilitators, who said that the advocacy training in particular was very useful for them. Training included:

- Presentation skills;
- Teambuilding;
- Action learning, which included participating in an action learning set to provide support around client casework;
- Advocacy training;
- Mental Health First Aid (MHFA);
- Designing and administering questionnaires;
- Running focus groups.

The Access Facilitators also attended six team building sessions with an external leadership consultant.

A number of colleagues from NHS Westminster and Kensington & Chelsea ran sessions designed to increase the Access Facilitators’ knowledge and awareness of health services. Sessions were delivered by NHS Westminster’s Sexual Health Development Manager (Sexual Health in Primary Care), NHS Westminster’s Project Manager for BME Communities and Mental Health – Improving Access to Psychological Therapies, NHS K&C PALS Service, K&C Early Intervention in Psychosis Team. Sessions were also run by Médecins du Monde UK - Project London.

**The Programme Activities**

**The Client Support Group**

A significant amount of time within the project has been dedicated to providing direct support for clients. The Access Facilitators worked with clients on a one-to-one basis to help them solve particular problems with accessing health services and improve their health.
Each Access Facilitators also identified 15 clients who were the subjects of a monitoring exercise measuring the impact of the Access Facilitators role in bringing about change for clients. They interviewed these clients in late August/early September 2009 and again in late March 2010.

The information collected initially helped the Access Facilitators formulate a clear understanding of the needs of the individuals concerned. It also provided insight into the problems faced by vulnerable BME people accessing healthcare in general. The information collected later helped monitor the impact of the support offered by the Access Facilitators.

Some of the experiences of members of the Client Support Group were developed into Case Studies, which are contained below.

The interventions provided to the Client Support Group included advocacy, language support and interpreting, as required, the provision of health information, signposting and referrals to other service providers.

Case Studies

These are a sample of case studies from the one-to-one work of the Access Facilitators with clients.

Al Hasaniya

1. Referral Details: A middle aged woman who had had a brain tumour successfully removed six years ago. The client was required to undergo a brain scan every year to check that the tumour had not returned. After five years of clear scan results the client was discharged from the department. However, she came in to say that her headaches had suddenly returned.

**Outcome:** Al Hasaniya called her consultant’s department and described the symptoms. The client was given an appointment for a brain scan the following day.

2. Referral Details: A middle aged woman who was being treated for severe depression and post traumatic stress disorder at the Assessment Services at Paterson Centre. The client came to ask for help to make a call in order to book an interpreter for her next appointment at the Paterson centre.

**Outcome:** Al Hasaniya called on her behalf and the receptionist was very rude, stating that the client should not need an interpreter after living in the UK for 25 years. They told her that this is not the first time that the client has been provided with an interpreter for appointments at their centre and the receptionist agreed that one would be provided.

3. Referral Details: A middle aged woman came in explaining that she had undergone dental treatment and believed that she was entitled to free treatment because she was in receipt of Incapacity Benefit.
The client had subsequently received a letter informing her that not only was she liable to pay the dental charges, but that she was also liable to pay a penalty charge for falsely claiming entitlement to free treatment.

She had brought copies of all her documents to Al Hasaniya who was able to establish from the original form that she had in fact ticked the box claiming she was in receipt of Income Support. The mistake was explained to her and they realised that she did not understand the difference between the two benefits. The difference was explained to her as well the fact that she was therefore not entitled to free treatment without an HC2 certificate. They called on her behalf and arranged for an HC1 form to be sent to her so that she could make the correct claim.

Once the client received the HC1 form she took it to Al Hasaniya who helped her to complete it. They also sent an accompanying letter explaining the mistake that she had made by falsely claiming free treatment and requested that she be permitted to pay the dental charge but that the penalty charge be withdrawn.

**Outcome:** The client was sent an HC2 certificate entitling her to full help with health costs from the date that it had been initially awarded. However, she was informed that she would have to pay for the previous treatment and also the penalty charge.

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**Chinese National Healthy Living Centre**

1. **Referral Details:** A woman suffering from arthritic pain and a number of other issues, unable to work since July 2009. She was receiving regular physiotherapy at the Soho health centre which had been arranged by her GP.

The client’s GP spoke Cantonese which made it easy for her to communicate and she was well looked after in the last few years.

On 21 January this year she was referred to an Ear Nose Throat (ENT) appointment but she lost her appointment letter. Chinese National Healthy Living Centre (CNHLC) phoned the hospital on her behalf and was informed of the time of the appointment was in a few days time.

**Outcome:** The client was able to get to her appointment on time, narrowly avoiding missing it. CNHLC also booked an interpreter for her physiotherapy appointment the following month and supported her to reschedule a breast screening appointment at St. Mary’s hospital.

2. **Referral Details:** An elderly man who was registered with a private dentist but was reluctant to make an appointment because of the high costs.

**Outcome:** CNHLC provided the Client with information about several local NHS dentists and how to make an appointment. As the Client spoke reasonable good English he was able to make an appointment by himself.

3. **Referral Details:** An elderly woman received a letter stating that she had a choice to opt out of eye screening test.

The client did not understand the previous letters inviting her for eye screening tests and did not respond.

**Outcome:** CNHLC were able to help her to telephone the Westminster diabetes centre and to book a test the following month.
4. Referral Details: An elderly woman who had been registered together with her husband at the same GP was removed from the registration list. Both the client and her husband had been registered with this GP since arriving in the UK 20 years ago. Over the past few years as she had generally been in good health she had not visited her GP. She was not made aware that she had been deregistered and it was only while CNHLC were helping her to report her lost medical card that she discovered what had happened.

Outcome: CNHLC explained to her that she had been removed from the system and what the process was for reregistering. An appointment was made and a follow up check was also booked for her with the practice nurse. CNHLC also booked a comprehensive check-up for her with an interpreter present, two weeks later.

Midaye Somali Development Network

1. Referral Details: A woman had been diagnosed with a rare spinal disorder where spinal fluid is drained, thereby weakening all the bones in the body, reducing mobility and nerve signals, and impairing the client's speech, walking, and independence. She had a seven year history of struggling with this degenerative disease and required support to liaise with her GP and the various hospitals where she had appointments. Although this client had a very good understanding of the English language and was able to hold a conversation with doctors about general subjects, problems arose when doctors used professional jargon, which she did not understand. Her lack of understanding of technical terms and a fear of being labelled as incompetent resulted in her requiring a range of support, including interpreting, advocacy and explaining the content of letters. She had also been misdiagnosed and prescribed antidepressants for five years and as a result had developed a dependency on them.

Outcome: Midaye learnt to work successfully with this client who often exhibited challenging behaviour and to explain her needs to health professionals. The client’s needs are chronic and Midaye will continue to support her and encourage her to participate in workshops and activities designed to have a positive effect on her well being.

2. Referral Details: An elderly woman who does not speak any English, and who suffers from severe arthritis and a recent back injury, slipped in the bath and severely injured herself. She was taken to A&E by a relative and on discharge was told that she needed to be seen by a GP. After trying to get through to her GP for two consecutive weeks, and a return visit to A&E, she contacted Midaye. The client was not able to read or write, so relied on Midaye to translate all correspondence, including medical letters and leaflets. In addition her poor memory necessitated that she be regularly reminded about appointments. She was unable to ask for an interpreter to help her to book or cancel appointments.

Outcome: Midaye was able to book an appointment for her the following day. Two members of staff went to the Client’s home and waited with her for the GP for half an hour after which the GP was contacted. It transpired that they had forgotten to book the visit and it was rebooked for the following day. Midaye contacted PALS to alert them to the issue, PALS also contacted the GP and the appointment took place the following day.
3. Referral Details: A woman whose son, in his early twenties, was diagnosed with severe bipolar disorder, moved from Birmingham to Kensington & Chelsea because she struggled to find appropriate services that would meet his need. She sought a GP in her local area, information about the local mental health services. She also had educational and housing needs. Although this client struggled with English, she knew from experience what services she needed. She had the responsibility of being a full time carer for a volatile young man, which was a major restriction on her.

Outcome: Midaye was able to refer her to a well regarded GP in her catchment area, refer her to the mental health services, and to suggest some ESOL classes which she would be able to attend. This client was also given information about workshops and was eager to attend the ongoing sessions on Mental Health, in order to broaden her knowledge and be able to understand and find alternative ways of coping with her son’s illness. She attends the drop-in sessions less and less each week which is a sign that her needs are being met.

4. Referral Details: An elderly man suffering from throat cancer who is a regular service user. He has a basic understanding of the English language but when under a lot of stress loses his command of the language. This client has relied on regular advocacy support at appointments in order to avoid professionals misunderstanding him and misinterpreting his “rants” in Somali, and behavioral changes as signs of severe mental illness as had occurred with his GP previously.

Outcome: Midaye was able to refer this client and his family for family therapy, and support him to access counselling. They also provided outreach support and mediation to clear up the misunderstanding with his GP.

5. Referral Details: A young woman diagnosed with rheumatism, who had a quite a good command of English. However, she had not been in the UK for very long, did not understand how health services worked or where to seek the help that she needed. When her GP first diagnosed her with rheumatism she left without fully understanding what this meant and consequently had not asked the GP to explain the condition. A few weeks later she returned to her GP surgery complaining of the same pains in her joints, and again the GP explained to her that she was suffering for early onset rheumatism. He prescribed her some paracetamol and some ibuprofen, but the client remained unaware of what was being said and became distressed. She attended Midaye complaining that her GP did not understand her and that he was negligent.

Outcome: Midaye provided outreach support to her at her appointment at the GP. The GP explained that on numerous occasions the client had visited him and each time she seemed as though she understood what he had said to her. Midaye explained to her what the diagnosis was and that there was no cure. This client has since been looking at alternative measures to lessen the pain caused by rheumatism and her relationship with her GP has drastically improved. The GP now arranges for an interpreter to attend with her.

6. Referral Details: A newly arrived migrant who was five months pregnant, not registered with a GP and had not been seen by a nurse. On arrival in the UK four months before, Immigration Officials overlooked her pregnancy.
This client was unable to speak English and was homeless following the breakdown of an abusive marriage. The client had no proof of residence or a passport.

Outcome: Midaye referred the client to the maternity unit at the local hospital for emergency checks because she had not received any until this point. The hospital staff and social services identified a GP for her; however, it took two weeks to register her due to the lack of requested documentation. Midaye also supported her with her accommodation needs and she was placed in a temporary accommodation in a hostel. When her child is 6 months old, the client will be enrolled onto ESOL courses to improve her English.

Queens Park Bangladesh Association
1. Referral Details: An elderly wheelchair bound woman who required her mattress to be replaced but was caught between her GP and the Social Services, both of whom refused to take responsibility for the case.
   The client first approached the Social Services to help her with the situation but was told that she needed to contact her GP. Her GP told her that her need was the responsibility of social services. The client attended a joint consultation session held by NHS Westminster and Westminster City Council. At this session she raised her concerns.
   In addition, this client has also been waiting for over a year for redecoration to her house by Westminster City Council. She had received a letter more than a year ago stating that someone would be carrying out the work.
Outcome: The client was asked to put her case forward through Queens Park Bangladesh Association (QPBA) via email to one of the professionals who was at the session. QPBA emailed the all the details to the NHS Westminster representative and is yet to hear from them. QPBA also contacted Westminster City Council regarding the redecoration and is awaiting a response.

WSPM Agape Community Projects
1. Referral Details: An elderly lady had a complaint about being prescribed the wrong medication by a locum doctor while her GP was away on holiday.
Outcome: WSPM Agape (WSPM) intervened on her behalf by accompanying her to the GP Surgery and providing her with support to explain what had happened. The client was provided with the correct prescription.

2. Referral Details: A young woman had concerns about her GP failing to provide her with test results.
   Her sister had been diagnosed with breast cancer and she was waiting for the results of the same test. She anxiously telephoned the surgery for the results. The receptionist mentioned something but the lady was not fluent in English and did not understand what the receptionist said.
Outcome: WSPM accompanied the client to the GP, where it was explained that her test results were negative and that she did not have cancer.
3. **Referral Details:** A young pregnant woman attended the centre seeking information and support to register with a dentist.  
**Outcome:** WSPM referred the client to a local dentist where she is now registered.

4. **Referral Details:** An elderly gentleman who was diagnosed with prostate cancer. He was told that he would have to undergo surgery and required support to help him with the process.  
**Outcome:** WSPM advocated for the client at his hospital appointments and was also able to provide him with information and support around aftercare following his operation. The client also attended the Project for counselling sessions and has since made a full recovery.

**What are the findings of the case studies?**

A lack of English language competency has a direct impact on people's ability to manage their health. For people suffering from prolonged or chronic illnesses in particular, the inability to articulate their needs in English affects their awareness of what services are available and how to make optimum use of these services. Delays in accessing services can prolong and/or exacerbate illness and delay recovery. Lack of knowledge and understanding is one of the root causes of inappropriate use of health services such as repeat GP appointments, failing to attend appointments or attending A&E for minor illnesses.

In order to negotiate complex health care systems, patients have to deal with very complex information and treatment decisions. These require an understanding of written instructions and doctors' directions. Furthermore, patients need to be able to describe their symptoms and articulate their health concerns accurately. They must be able to ask pertinent questions, and understand diagnoses, instructions and medical advice. Interpreters and language support are therefore crucial to improving the health of BME communities.

In marginalised communities, there are widespread problems with regard to patients being unaware of their entitlements. Repeated questions from clients were: ‘Am I entitled to register with an NHS dentist?’ ‘Am I entitled to free medication?’ ‘How do I fill out these forms?’ ‘Where can I find this information?’ These barriers inhibit people’s willingness to find an NHS dentist or to go to the doctor. Furthermore, poor GP-patient relationships are often made worse because patients are unaware of their relevant entitlements, such as knowing that a GP can be changed, a second opinion sought, and that the process for doing so is simple and short.

Disseminating understanding of how to use systems among disadvantaged and marginalised communities is a role that can be most effectively tackled by adopting a community development approach. Community organisations are in the strongest position to educate and share information with their communities. A community development approach engages the issues from the standpoint of direct experience, and is therefore better placed to solve the problems than from the outside “looking in”.

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In conclusion, a range of issues have been evidenced through these case studies, which provide an opportunity to look at the prevailing issues that affect the communities represented on this programme. The issues of communication and understanding of entitlements are critical to all communities. In order to bridge these gaps, it is essential that the NHS works with community organisations who can act as cultural brokers to their communities. Furthermore, well funded ESOL for health programmes and capacity building for organisations will help diaspora communities to achieve independence.

**ESOL for Health Workshops**

The purpose of this output was to pilot and test this method of improving the understanding of health and health related language amongst service users and members.

*‘The ESOL for health session went down really well. I am discussing with the local college whether we can have it as a certified course. It was very empowering and there was a lot of good feedback.’*

(Senior manager, community organisation)

The sessions were planned in partnership with Migrants Resource Centre (MRC) and were delivered by Ambra Caruso and Catheryn Cheetham of MRC. MRC had already been delivering these sessions as a component of their general ESOL language course taught by a CELTA qualified language teacher.

ESOL for health are one-off sessions which were adapted according to the specific cultural needs and level of English of the learners, and the feedback instructors received from previous sessions. The GPAW programme aimed to deliver sessions to a target of ninety participants in total.

However, the uptake from community members was not as good as had been anticipated, because there was little enthusiasm amongst community members to attend a one-off session despite the Access Facilitators trying to encourage attendance. It also became apparent that members were reluctant to travel away from their local area rendering it impossible to achieve a mix of communities.

As a result the programme attracted only 40 participants. The feedback from each session has been very good, but the general consensus was that this type of session could be better delivered as part of a funded ESOL class.

Overall the participants who did attend stated that they found the sessions very useful and gained a better understanding of:

- NHS services
- How to communicate with health service providers

- How to register with NHS GPs and Dentists
- The right to an interpreter
- English health language and terminology

Instructors Ambra and Catheryn enjoyed delivering the sessions to the communities, they said “Delivering the ESOL for Health sessions for the GPAW project was a fun and rewarding experience. The participants were all keen learners and tried to make the most out of the sessions. The Access Facilitators were very supportive and helped the students whenever needed.”

The general consensus amongst both the Access Facilitators and the participants was that this type of programme is very important and would help empower BME communities.

**Chinese National Healthy Living Centre:** Hosted one session. Activities included completing actual registration forms, learning common terms used at GP and dental clinics, and learning about patient responsibilities. Copies the HC 11 form were introduced to help learners to understand health costs.

**What worked** - Participants were engaged throughout the session and the feedback was positive. They enjoyed and understood the session and found it very interesting and useful. The feeling was that ESOL for health is a tool that can be used to support individuals to manage their day to day health care issues. CNHLC feel that if this activity were to be delivered on an ongoing basis, as a course, there would be a demand from their clients to attend.

**What could be improved** – Individuals with very limited English, and no literacy would not be able to grasp much of the content; perhaps a special session using simplified formats, could be designed to enable them to benefit.

**Al Hasaniya:** Hosted two sessions, one on Health Vocabulary and one on Healthy Eating

**What worked** - The women who attended the sessions found both sessions interesting. The need for ESOL provision is great and urgently needed by BME communities.

**What could be improved** – Al Hasaniya did not have much success in sending their community members to sessions held outside their centre and only one woman attended such a session.
Al Hasaniya describes their users, as being a very vulnerable group: ‘most of our women suffer from physical and/or psychological disabilities which inhibit them from travelling around the city and lead them to feel unsafe outside their familiar spaces’

The women felt it would be much better if the classes were incorporated into a longer more comprehensive course, where the topics could be explored in more depth and contextualised within a broader learning programme.

Midaye: Due to lack of space, Midaye were not able to host any sessions, but they supported their members to participate in some of the other sessions.

What worked – The feedback from the Somali women who attended was that the classes were more useful than regular ESOL classes and would help them communicate with their GP. It was suggested that ESOL for health should be incorporated into the mainstream curriculum for ESOL classes, as the material was more relevant and useful for the Somali community than much of the material which is currently taught in regular ESOL classes, which is regarded as trivial to many in the community.

What could be improved – Midaye felt that that ESOL for Health should be integrated into mainstream ESOL provision, as one-off sessions provide less benefit to their community.

If mainstreamed they would provide a means of greatly empowering minority communities while lessening the burden on the NHS to fund interpreting services. Mainstream ESOL sessions could also be adapted to meet similar needs for knowledge and information in other fields besides the health service, such as the education, housing and immigration systems.

“Midaye would like to reiterate that ESOL for Health is of crucial importance, ... we feel that these are much more important than much of which is provided on the current curriculum [of ESOL classes].”

Queens Park Bangladesh Association: Hosted one session, which was very successful. They also encountered great difficulties in trying to recruit service users to attend sessions outside of their centre. Many of their clients are vulnerable elderly people for whom travelling any distance is problematic.

What worked - The session was oversubscribed, and two clients had to be turned away, due to lack of space. The participants said that they “enjoyed it very much”, and wanted to know if QPBA were delivering any further sessions.
What could be improved – Any future sessions should make provisions for sufficient room for all participants.

WSPM Agape: Hosted an evening session for people who understood English at an advanced level. Participants enjoyed the session and articulated that they had learnt many new things about the NHS, entitlements, help with health costs, making a complaint and how to access other services. The session included many exercises designed to reinforce the learning process.

What worked - Interaction between the participants and the instructors was very good; participants felt empowered to ask questions. They also felt the way in which the session was structured, the pace and delivery was very good. The trainers delivered the course very well and knew their subject matter, which was of value to the learners. The highlight was the quiz about body age versus the actual age, which was linked to a healthy lifestyle, everyone enjoyed it. All participants agreed that the ESOL for Health session was beneficial to the community.

Health information for Communities

The six community organisations delivered a number of activities which have helped to explain how to access health services. The content of the sessions were designed to deliver specific health information needs to communities. The groups delivered two joint sessions to raise awareness of access to health services, and access and awareness of Mental Health services. Both events were delivered using the ‘café’ style model.

The first session, Access to Health Services: An Overview was held in November 2009 and provided information to communities on: Drugs & Alcohol, Dentists, the role of GPs, Environmental Health, Pharmacists, NHS Walk in Centres and NHS Charges.

In February 2010 the group ran an Access to and Awareness of Mental Health Service workshop. Presentations were made by the following organisations: Advocate for Mental Health, Carers Network, Community Mental Health Team, Increasing Access to Psychological Therapies, NHS Westminster Health Improvement Team, Oremi Centre Westminster Advocacy Service for Senior Residents and Westminster Mind: (Portugal Prints & Aldwych Enterprises).

All projects also ran at least one focus group entitled: ‘You are entitled to free NHS health care at the point of use'. Five of the projects also delivered a session on NHS Complaints, PALS and the constitution.
‘Our clients very much appreciate the help and advice on health issues which are made available to them through our programme of regular workshops. Almost all our women suffer from physical and mental health problems which affect their daily life and sense of well-being.’

Al Hasaniya Moroccan Woman’s Project

The Publications

Interpreting guide
The groups collaborated together to identify key themes for the production of an interpreting guide for their communities. The guide is targeted to community members who use interpreting services as well as their families and friends who often act as informal interpreters.

The design was chosen to appeal to young people, since they are commonly the people who interpret for parents and older relatives. The guide is written in plain English so that it can be read by people who read English at a low level and it was translated into five community languages (Arabic, Bengali, Chinese, French and Somali).

The interpreting guide explains the benefits of using formal interpreters instead of informal interpreters, gives information on how to access a formal interpreter, using examples from the Programme’s case studies it demonstrates how the use of a formal interpreter can help clear up miscommunication between doctors and patients and therefore improve the patients’ health and experience of services.

An audio version (CD) of the publication was discussed at the development stage of the process but it was felt by all but the Chinese project that it would not be an effective way to deliver the information.

NHS Factscards
The information collected from the questionnaires, focus groups and 1-1 case work with clients/members formed the basis of the health information that was included on a collection of cards, which were printed in 6 different languages.
The information on the cards related to each of the 6 community groups and their main health problems and also provided information on accessing services including GPS, Dentists, Maternity Services, Mental Health Services, Chemists, Walk in services and PALS. Each set of cards was designed to represent its corresponding community in terms of colours, symbols and imagery.
In order to publicise the important message of not using children to interpret we produced a poster aimed at children and adults which delivers the message in a light hearted way. It depicts children enjoying the right to be children and not having to do an "Adult’s Job".
Conclusions

Action to reduce barriers to effective communication remains key to improving the health experience of BME communities and addressing persistent health inequalities. Interpreting provision needs to be of high quality, better regulated, and more widely disseminated to service providers and communities. There needs to be a greater emphasis on health education in culturally appropriate and user friendly formats. BME communities need to learn the language of health which will empower them to communicate to speak up about their conditions.

Additionally, our experience of the successes and shortcomings of the programme leads to a core set of recommendations for a significant change to the way that primary care services are commissioned. Such change will lead to effective engagement and produce sustainable and long term improvement.

We strongly recommend the adoption of a community development based approach to underpin the governance and management of primary health care services, following the Community Health Centre (CHC) model which has been in operation in Canada for more than thirty years and has proven success.5

CHCs are voluntary organisations that offer local people a number of services, including health services, and are specifically aimed at communities that face barriers in accessing primary care. CHCs are multi-disciplinary so that:

"they support clients not only by providing clinical services but also by dealing with the social, environmental and economic determinants of health... are community led, accessible ... and work under explicit anti-oppression policies ..." 6

Adopting a sustainable cultural brokerage model (refer to page 14) alongside the CHC model of governance will provide a solution to the barriers experienced by BME groups. For example:

- Such a model will facilitate cultural change amongst both service providers and recipients;
- It will enable communities themselves to inform the provision of health services based on their unique ability to understand their own health needs;
- It will enable BME communities to learn the language of health and to empower them to communicate effectively about their needs;
- It will also enable providers to understand the context, culture and values in which their service users function, in order to provide effective care.

6 Ibid
Recommendations

These recommendations are complemented by the recommendations of the independent evaluation, which are also listed in Appendix 3.

Recommendation 1

All stakeholders should work together to implement a model for the governance of primary care services which is based on the Canadian Community Health Centre (CHC). This should, in the first instance, be led by the Primary Care Trusts (PCTs) and Practice Based Commissioning Groups (PBC) in the context of their programmes for the development of community based services.

Recommendation 2

In addition to developing a Community Health Centre (CHC) model commissioners should ensure BME communities are actively involved in all service developments, at all stages from inception to evaluation. This will help demonstrate World Class Commissioning competencies and meet Public and Patient Involvement requirements and Equalities Duties.

Recommendation 3

Stakeholders should use a community development approach for engagement with BME communities (refer to page 13).

This will include providing appropriate resources for:

- dialogue with community organisations, particularly around difficult to engage issues;
- Dissemination of key health messages;
- Close partnership with community organisations in the delivery of preventative services, including screening services and procedures;
- Recognising the importance of actively engaging children and young people as key stakeholders in promoting good practice.

Recommendation 4

Commissioners should adopt a cultural brokerage approach (refer to page 14) and support community organisations to develop the skills and capacity required to deliver this effectively.
Recommendation 5

BME Access Facilitators should be recruited and co-located in GP surgeries and community organisations with the remit to educate and support communities and health professionals. This will facilitate greater access, improve communication and increase understanding.

Recommendation 6

To ensure BME communities and health professionals continue to benefit from the output of the GPAW project, there needs to be:

- A commitment from the two PCTs and other key stakeholders to reprint, disseminate and embed use of the interpreting guides and fact cards;
- A commitment to produce the GPAW literature in other community languages, in addition to the six included in the programme.

Recommendation 7

Based on the success of the existing course, ESOL for health should be continued and extended to improve health literacy. This model needs further development to spread and sustain good practice.

Recommendation 8

Commissioners and the BME Health Forum should work in partnership to develop a training package for commissioners and providers. Training should focus on how best to support and develop community organisations in addressing barriers to health access and resulting health inequalities. This package should incorporate:

- The barriers to equitable access;
- The link between barriers to access and health inequalities;
- Best practice in the approach to supporting community organisations to address these barriers;
- The role of cultural brokerage in reducing barriers.
**Recommendation 9**

Second tier community and voluntary organisations should be funded to provide additional infrastructure support to BME communities and community voluntary organisations, in order to work in collaboration and promote partnership to address shared health and social issues.

This will support community cohesion and increase the capacity of groups who often have a common purpose. There would also be a less burdensome transactional cost involved if community groups could work as a consortium when submitting funding applications in the current uncertain economic climate.
Appendix 1
Community Projects Final Reports

Here are some extracts from the community groups’ final reports

Queens Park Bangladesh Association

The approach of the project and its bottom up approach to engaging the community has had an empowering effect on both the community and the organisation. With the GPAW programme being a pilot programme which has only lasted a year, the work produced has been successful. Other than the users who received one to one support around accessing health services and welfare benefits, the majority who attended health sessions found it to be more effective for them when the sessions were interactive and informal.

Some clients were a challenge to engage because they did not want to increase their knowledge on certain topics as they thought it was not of relevance. However, overall the users said that they benefited from the information and support received from QPBA but felt that the GPAW programme should been more of a benefit on individual issues. It was also difficult to tailor the project to address only health needs when there were many other factors that were having an adverse effect on the lives of our users, for example we had a client who suffered from ill health and language barriers to accessing services but was more concerned about her housing then health. In order to overcome issue we integrated aspects of a number of other projects to complement the health aspect. Engaging the community worked really well, as we were already engaging a lot of the community it provided a good starting point.

Unfortunately local GPs were reluctant to work with and take part, but QPBA managed to meet with a local GP at the Queens Park Health Centre and discuss the possibility working together. The issue of interpreting was bought up at the meeting and the GP reiterated that it is harder for them to communicate with the patient if there is a formal interpreter present. The GP suggested that this is because the patient does not open up or is unable to express themselves in the same way with an unfamiliar third party present but agreed with us that using children as interpreters needed to stop and would support us in this endeavour.

It can be said that overall, by QPBA taking part in the GPAW programme it has meant that other related work has developed from it for the future. The GPAW programme has enabled QPBA to address needs of the community identified and put itself in a better position to tailor projects that will be effective in engaging the Bangladeshi community.

WSPM Agape

Regular meetings with the coordinator and information sharing with the other community projects was very helpful, it was also enlightening and rewarding working with other organisations, knowing that the programme would help BME communities.
The training courses on Advocacy, Presentation skills and Mental Health First Aid were very productive, comprehensive and helpful, the knowledge has been incorporated into the organisation on a wider scale and there are daily surgeries of advocacy, clients and beneficiaries are more inclined to come and ask for advice on health issues. They are aware of how to raise a concern or make a complaint and the role PALS have concerning the NHS.

Clients and beneficiaries have gained very good knowledge about formal and informal interpreters and the advantages of using formal interpreters and the disadvantages of using informal interpreters, healthy eating & exercise, and have also gained knowledge about NHS services through the ESOL for health classes which they found very good and have asked for more classes.
The presentation on the Mental Health Act delivered by WSPM for the Mental Health Awareness Workshop was very good experience, participants were engaged and found it very helpful. WSPM has extended its advocacy advice surgeries to include information on health.

Overall GPAW has been a success in the terms of interaction, knowledge, experience, information gathered and the ongoing projects. Clients and beneficiaries are in a much better position and much more confident about their awareness of the NHS and services provided. It is hoped that although it was a pilot programme, the information gathered and the expectation of the clients and beneficiaries would enable the NHS to provide and make sure BME communities have better access to such services also realising that community groups play a vital and important role in such provisions being made.

Al-Hasaniya

The advocacy training and action learning we received at both Supported Voices and MRCF were illuminating and stimulating. The Supported Voices training afforded us the opportunity to take with us a complex and confusing case study we were dealing with at the time and share the questions and issues it raised with everyone present. The feedback was presented in such a way that it deliberately did not present answers, but instead formed questions to explore the possible ways of moving forward from the point of view of the client and his/her individual needs and circumstances. The trainer at MRCF shared with us a very personal experience of working as an advocate in mental health settings and looked at the challenges and strategies involved in helping someone with particular emotional and mental vulnerabilities.
Appendix 2

Key findings from the Independent Evaluation Report:

The following results are based on a total of 325 responses, collected from the community organisations. Not all clients answered every question.

Interpretation

Of those surveyed, 41% said they needed the support of an interpreter to communicate with their doctor or other health professional, while 18% said that they ‘sometimes’ needed this support, as shown in the chart below.

![Pie chart showing support needed for communication with doctor or health professional]

Base: 302 respondents

Of the 177 clients who said they needed the support of an interpreter (including those who ‘sometimes’ needed support), 86% said that they had used an interpreter before. Of these, 50% had used an informal interpreter.

![Pie chart showing use of formal or informal interpreters]

Base: 145 respondents

13 ‘Evaluation of the Shared Leadership (BME) Scheme for Kensington & Chelsea and Westminster BME Health Forum’, Shared Intelligence, November 2009
However, this varied a lot by organisation, with the Chinese National Healthy Living Centre and the Kongoolese Centre most likely to use formal interpreters (although when broken down this way the numbers are quite small, so care must be taken in using these findings to generalise). It has been suggested that, in the case of the Chinese National Healthy Living Centre, this might be because a lot of work has been done to signpost users to formal interpreters.

Of the 17 clients who said they needed interpretation support but hadn’t used an interpreter before, 10 (62.5%) said they weren’t aware that they were entitled to ask for a formal interpreter.

For people who had used an interpreter before, two of the main problems involved in using or asking for an interpreter were finding an interpreter who speaks the same dialect (40%) and knowing where to ask for an interpreter (39%). Other problems included having to give advance notice; interpreters not turning up and patients therefore missing appointments; and generally not being offering an interpreter.

**Accessing NHS services**

The majority of respondents were registered with a GP (89.2%), but only 55.4% of respondents were registered with an NHS Dentist.
This also varied quite a lot by organisation, with 67% and 54% of respondents from the Chinese National Healthy Living Centre and WSPM Agape (respectively) not registered; compared with only 11% of Queens Park Bangladeshi Association.

One of the main reasons for not being registered was not being sure they were entitled to, closely followed by not being sure where the nearest NHS Dentist was located. However, other reasons were largely around the fact that respondents did not see the need to go to the Dentist if they didn’t have any problems with their teeth. Some also said they weren’t sure how the system worked or were scared about the treatment. The reason that so many Chinese respondents were not registered with an NHS Dentist was that they were often registered with a private Chinese Dentist, who they trusted more.

With regards to knowing where to find NHS services, 56% of respondents didn’t know where to find their nearest NHS walk-in centre and 21% didn’t know where their nearest Accident and Emergency services were. Most people felt either very or fairly comfortable talking to health professionals about their health, but some of the things that they said would make them feel uncomfortable included not having enough time to go into something that is worrying you; health professionals not listening to patients; or not having a female doctor.
Improving access for BME communities

A lot of the work that the project has done focuses on improving access to health services for BME communities in the longer term, through gathering evidence and identifying good practice that will be used to engage and influence NHS professionals in future. However, it has been possible to explore how the project has helped individual clients who have received direct support as part of the project. This section therefore provides findings on client outcomes and benefits.

Client feedback on support

Of the 310 respondents to the final survey, the vast majority (90%) said that they had received help solving a problem that they had. Two thirds (66%) said that they had received information on NHS services; and just under half said that they had received information on other organisations who could help them (45%) or had been referred to other organisations (47%).

Almost all respondents said that the support that they had received was useful, with 83% saying that the support they received was very useful and 14% saying it was fairly useful.

Respondents were asked what they had found most helpful about the support. Several said that being able to access support in their own language, and having a culturally sensitive service, was particularly helpful. They felt that the Access Facilitator could fully understand their situation.

‘I find staff are friendly and approach my concerns with care. I also find it very useful to have support services speak to me in my mother tongue which makes it easier to communicate.’

‘They speak my language and understood my situation.’ (Survey respondents)

Many respondents said that they felt that they had benefited from having a dedicated worker, who understands their problems. They said that they had found the Access Facilitators friendly and approachable, and willing to help whenever they needed their support.

‘I have found that staff genuinely care about my concerns and help me whenever I need the support. I also find helpful to have the same support worker which is reassuring as I do not have to keep explaining my issues to new workers.’

‘[They are] very knowledgeable and supportive. They take time to treat you like a human being not as a statistic. Very few agencies have that approach now. Everyone is busy ticking boxes!’
‘They are friendly and reachable any day of the week.’
(Survey respondents)

In addition, several respondents said that it was helpful to be able to go somewhere where the support was under one roof – a convenient way of getting help with different problems, including health services, housing, and benefit advice.

‘More convenient to consult and get information here than go to hospital, direct help, easy to communicate.’

‘They supported me in many issues and helped me sort everything out.’
(Survey respondents)

As such, the majority of respondents (94%) said that the support they had received had helped them to solve an issue that they had, and almost two thirds (63%) said that the support had made them more aware of NHS services. Just over half (53%) said that the support they had received made them feel more confident generally.

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<tr>
<th>Did the support you received help you in any of the following ways?</th>
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<tbody>
<tr>
<td>Helped me solve an issue I had</td>
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<tr>
<td>Made me more aware of NHS services</td>
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<tr>
<td>Made me more aware of how to get an formal interpreter</td>
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<tr>
<td>Made me more aware of how to make a formal complaint</td>
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<tr>
<td>Made me feel more confident generally</td>
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<tr>
<td>Made me more able to book an appointment where I needed to</td>
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Analysis of the open comments to the survey also suggested that an important benefit of the support was around social interaction; several respondents commented that they had been given the chance to meet other people in the same position as them, and it was comforting to knowing that they had similar problems and that they could be solved.
‘There are spaces for users to socialise with friends. It is very important for communities like me who cannot speak English to meet friends and be active. I enjoy my time here.’

‘I know from the workshops there are a lot of people with similar problems to me.’

(Survey respondents)

Other comments suggested that knowing that the Access Facilitator was there to help had been very comforting, and helped to taking the burden and worry away.

‘I feel more confident knowing people were there to support and help me.’

(Survey respondents)

Knowing where to find and when to use services

Analysis of the survey responses shows that the support provided to clients has helped to make them more aware of where different NHS services are located in their area. As shown in the chart below, for example, only 28% of respondents prior to receiving support knew where their nearest NHS walk-in centre was, but this has increased to 49% following support. Similarly, 24% of respondents didn’t know where their nearest NHS Dentist was before receiving support, but this decreased to only 7% after receiving support, when 93% said that they knew where their nearest NHS Dentist was.

![Chart showing proportion of clients who knew where services were located before and after support](chart.png)

Respondents were also asked if they knew when to use the different NHS services. In the baseline questionnaire, before receiving support, 21% said that they didn’t know when to use Accident and Emergency Services, but this had decreased to only 8% after receiving support.
In addition, only 28% said that they knew when to use an NHS walk-in centre before receiving support, and this had increased to 46% after receiving support.

Some respondents made additional comments. These also backed up the finding that the support had been helpful in making people more aware of different NHS services and more confident in accessing them.

‘The most helpful support [has been] to help me to understand NHS system better, so that I can ask for appropriate services.’

‘I feel more educated on the NHS and what they do. And I feel more confident in using the NHS when I need to.’

‘I did not know about that much about walk in centres before, this information has helped me.’

(Survey respondents)

Registering with a GP and an NHS Dentist

In the baseline survey, before receiving support, the majority of respondents (89%) were registered with a GP, but only 55% of respondents were registered with an NHS Dentist.

One of the main reasons for not being registered was not being sure that they were entitled to register (30%), closely followed by not being sure where the nearest NHS Dentist was located (26%).
However, other reasons that came through in the open comments were largely around the fact that respondents did not see the need to go to the dentist if they didn’t have any problems with their teeth. Some also said they weren’t sure how the system worked or were scared about the treatment. In addition, the reason that so many Chinese respondents were not registered with an NHS Dentist was that they were often registered with a private Chinese Dentist, who they trusted more. After receiving information and support from Access Facilitators, 81% of respondents said that they were now registered with an NHS Dentist.

*Staff helped me to find the nearest NHS dentist to where I live and explained the cost system. This could save me a lot of money whenever I need to see the dentist next time.’*

*(Survey respondents)*

**Understanding entitlements to interpretation services**

Of those who said they needed the support of an interpreter and had used one in the past, 50% of respondents in the baseline questionnaire, before receiving support, said that they had used an informal interpreter, and 44% had used a formal interpreter.

The baseline questionnaire also showed that some people experienced problems when using formal interpreters: 40% of respondents said that they had problems finding an interpreter who spoke the same dialect as them; 39% said that they had difficulties knowing where they could ask for an interpreter; and 32% said that they had a problem finding an interpreter that could help them with a particular problem. Other problems included having to book an interpreter in advance and interpreters not turning up on time.

After receiving support, 79% of respondents said that they had used an interpreter in the last six months, and of those, 63% had used a formal interpreter, suggesting that the use of formal interpreters has increased after support. Just over a third (35%) of these had had support from their community organisation in booking the interpreter, and 55% had booked them directly through the NHS themselves.

‘I now know that I have right to have an interpreter to come with me for appointment. I don’t need to ask for friends or family members who speaks English. This could save their time.’

*(Survey respondents)*

Of those who hadn’t used an interpreter, the majority (59%) did know that they were entitled to ask for a formal interpreter, but around two fifths (41%) did not. In addition, just over two thirds of respondents (68%) said that they didn’t know where to ask for help if they experienced any problems with interpreters.
Building the capacity of community organisations

A major focus of the project has been to build the capacity of the Access Facilitators – and in turn the organisations they work within – to support with their clients and communities to help improve access to health services. This section looks at the difference the project has made to the Access Facilitators and their organisations.

Impact on Access Facilitators

All the Access Facilitators said that they had benefited personally from being involved in the project. They said that through their experiences on the project, they had learnt more about their communities’ health needs, and how these compare with the other communities who were involved in the project.

Senior managers, in particular, felt that it was very enlightening to see the similarities and differences between different BME communities.

‘By working with the other five orgs, you learn from each other and appreciate the differences and similarities that BME groups are facing in this country.’

(Senior manager, community organisation)

In addition, through trialling different approaches, some felt that they had learnt about what works well in engaging members of their community and others said that they had learnt more about the NHS and the different services, which they were able to pass on to their colleagues and directly to their clients.

‘I have learnt things about NHS services that I didn’t know, and I think our clients have benefited from that. The information has been passed onto them, so they are more knowledgeable and more aware that they can ask questions and complain.’

(Access Facilitator)

The training that Access Facilitators received as part of the project was also useful in supporting them in their role and developing them personally for future work. As such, generally the feedback on the training was good, although some felt that it could have been even better if all the training had taken place at the beginning of the project, as originally planned.

‘The various training was all good for me – for now and for my future career too.’

‘As promised, we had lots of training. That’s all been good ... But because of the delays, we have another [training session] coming up ... it’s good to assist us growing, but it would have been good to have more at the beginning.’

(Access Facilitators)

Although some felt that the fortnightly PDG meetings were a little time consuming, and more could have perhaps been done by email, all the Access Facilitators thought that the meetings had been helpful in building relationships among the group and offering peer support where people were experiencing problems.

[The project coordinator] has been brilliant. We’ve been meeting up to check on progress ... Sometimes it’s a bit too frequent to meet every two weeks when it’s not busy and there’s not much to report. ... but the other Access Facilitators are quite helpful. I’m enjoying working with them.’

‘The meetings were excellent. We saw everyone else had the same problems and everyone would chip in with solutions – that was really useful.’

(Access Facilitators)

Impact on the community organisations more widely
The Access Facilitators and their senior managers felt that working on the project had helped to build relationships across the six community organisations, creating a large support network that they could draw on in future for help and advice, and to refer clients to where appropriate.

‘The meetings have been very helpful. I have made some contacts if I have any questions or need support. Knowing about the other organisations is useful so we can refer people to them and them to us. It’s been a good group.’

(Access Facilitator)

‘We’ve also benefited from the partnerships that have been strengthened across the six groups. From this we will hopefully be able to develop this work into something else.’

(Senior manager, community organisation)

For the organisations involved in the project, most were already doing work around health or had recognised a need to do more, and being able to employ a dedicated health worker had been extremely valuable for the organisation and for their clients, because it meant that this work could be more in depth than they would otherwise have been able to provide.

‘Without funding, we couldn’t have had a full time project worker.’

(Senior manager, community organisation)

‘I was interested [in getting involved in the project] because we do advocacy in other areas, but the health aspect was something we were interested in. In our community groups, there are a range of health issues that need to be addressed. We weren’t doing much on health before this project, not in depth.’

(Access Facilitator)

Challenges around future work and sustainability
All of the organisations valued their role in the project and said that they would like to continue the work because they had recognised how important it was through the project. However, all the organisations were facing challenges around obtaining funding and said that they would not be able to continue the work at the same level without further funding.
‘Realistically we can’t carry on the level of work – we will have to wait and see what funding is out there and what comes out of the final report. We’ll be seeking funds wherever we can.’

(Senior manager, community organisation)

In addition to funding, one of the other main challenges was that many of the community organisations felt that the work done through the project was really only the tip of the iceberg; they felt that they had only been able to touch on the issues in the time that they had available for the project and felt that there was so much more to do in future.

However, many of the Access Facilitators and their senior managers were concerned that the lessons learned from the project and the good practice that had been identified would not be taken forward. They hope that NHS commissioners would take notice of their report and its recommendations, but were sceptical about whether this would happen in practice. The implication of this, they felt, was that their clients and the wider community would begin to lose trust in them.

‘The only thing is that one of the concerns is that it’s not just a report that is shoved under the table – it’s about what do we do with all of these concerns. It’s ok for us to do this work but the commissioners need to understand this. I hope it’s not just another report. I hope it is something that can continue in future, because it would be such a shame. We build trust in the community and we will begin to lose trust and the value of what we are doing if it’s just another report.’

‘We will produce a list of recommendations in our report, but it will be very easy for that to just sit there and no one take any notice of it. Whereas if they looked at it, it would be something... We have asked something of our users, and they have put time into giving us responses, but one would hope that slowly in the future they will get some benefit from that.’

(Access Facilitators)
Appendix 3

Conclusions and recommendations of the Independent Evaluation

1. The Good Practices for Access and Well Being Project has been successful in improving access to health services among many BME clients who have sought support from the community organisations involved. As a result of the support they have received, clients are more aware of where NHS services are located and when they should use them; are more likely to exercise their right to use a formal interpreter when accessing NHS services; and many who weren’t sure if they were able to register with an NHS Dentist now have.

2. In addition, Access Facilitators and their organisations have learnt more about their communities’ health and access needs; have benefited from having a dedicated health worker; and have built relationships with other community organisations in the area who they can work with and approach for support and advice in future, should they need to.

3. But perhaps more importantly, the project has generated a considerable amount of learning about what works and what doesn’t work, and what changes need to happen in future to improve access to health services among KCW’s BME communities. Some of the implications of this are detailed below.

Improving access through community organisations

4. A major lesson that has been learned through the project has been the success of working with community organisations to engage BME communities. Clients said that they found the organisations and the Access Facilitators friendly and approachable, and they felt more comfortable talking to them about their problems in their own language and in a way that took account of their cultural and ethnic background.

5. Clients also valued the fact that they could get support on a whole range of issues under one roof – including support with booking an appointment with their GP, arranging for an interpreter to contact them, and help finding an ESOL course.

6. We would therefore recommend that in the future, NHS commissioners consider providing further funding to community organisations, in order to provide a route to engaging BME communities more effectively and improving their access to NHS services. One suggestion that has come through particularly strongly from the community organisations involved in the project has been to provide funding to community organisations for interpreting services, so that community interpreters are based within community organisations and are easily accessible to BME communities.

Long term change and sustainability

7. One of the difficulties with the project has been that it has only really scraped the surface in terms of meeting the needs of BME communities in the area. It has been a pilot project, to test out approaches, identify good practice, and develop resources, but there has been a limit to what could be achieved within the limited timescale of the funding.

8. The project has showed that a year of funding can make a difference, but that it isn’t really enough to achieve the longer term change that is needed to improve access to health services among BME communities and reduce health inequalities. Much of the time at the beginning of the project was spent setting it up, which only left a few months to do some of the more in depth work.

9. This is particularly true for the ‘ESOL for Health’ sessions, for example, which appear to have been useful for those who attended but have really only been introductory sessions. For these to make a real impact, clients would need longer term support.

10. We would therefore suggest that if NHS Westminster and Kensington and Chelsea PCT want to build on the successes and lessons learnt of this project, they consider providing longer term funding – at least two to three years – in order to make a bigger impact on reducing health inequalities.

Taking forward the project’s recommendations

11. The Good Practices for Access and Well Being project has gathered evidence, identified good practice and highlighted the needs of BME communities in KCW, all of which will be detailed in the project’s final report to commissioners and will be useful in deciding what changes and actions are needed in future to improve access to health services.

12. There is a danger, however, that this work could all be in vain if the project’s recommendations are not taken on board, and the community organisations are concerned that their clients will lose trust in them if nothing changes as a result of the time they have put in.

13. KCW BME Health Forum will play an active role in taking forward the project’s recommendations, strengthened by their involvement in the Shared Leadership Scheme and the work they have already done in building relationships with colleagues in the PCTs and improving their influencing skills.

14. We would recommend therefore that NHS commissioners work in partnership with the forum to understand the lessons learnt from the project and discuss their implications, to inform any future work in this area.
Appendix 4

BME Health Forum Terms of Reference

The BME Health Forum is a collaborative partnership between statutory, voluntary and community organisations that aims to improve health and reduce health inequalities for BME communities in KCW. The Forum aims both to empower communities to engage effectively in debate with the health services and to enable statutory services and health professionals to hear, understand and respond adequately to the health needs of BME communities. The BME Health Forum’s areas of work include:

- Removing barriers to accessing healthcare for BME communities both directly and indirectly by engaging with clinicians, health trusts, community organisations and patients, improving links and communication and raising awareness;

- Supporting BME communities and organisations to voice their health concerns, bringing these to the attention of commissioners and providers and ensuring that they are taken into account in the planning, commissioning and delivery of services;

- Supporting the voluntary and community sector in their delivery of health and wellbeing projects by a variety of strategies including commissioning, providing skills and information, demonstrating value and raising concerns to the relevant statutory sector bodies.

GPAW was designed to enable both the Forum and the Community Organisations to develop techniques and tools that would help community members overcome barriers to accessing health services.
DON'T ASK ME TO DO AN ADULTS JOB!!
CHILDREN SHOULD NOT BE USED AS INTERPRETERS

Good Practices for Access & Wellbeing