Listening To Communities: Involving People In Health

A programme of consultations with Asian, African, Caribbean, Chinese, Asylum Seeker and Refugee communities in Glasgow

Report Summary

June 2003

Report Prepared By: Lyndell Weaver – Community Research Officer
Multicultural Health Development Programme - Greater Glasgow Primary Care NHS Trust – 0141 211 3898

This work was developed in partnership between Greater Glasgow NHS Board, Greater Glasgow Primary Care NHS Trust and the Trust’s Community Forum For Equality and Diversity
## CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>WHY HAVE WE BEGUN 'LISTENING TO COMMUNITIES'?</td>
<td>2</td>
</tr>
<tr>
<td>WHO WAS INVOLVED?</td>
<td>4</td>
</tr>
<tr>
<td>AIMS OF THE LISTENING TO COMMUNITIES OPEN SPACE EVENTS</td>
<td>5</td>
</tr>
<tr>
<td>WHAT WAS THE PROCESS?</td>
<td>6</td>
</tr>
<tr>
<td>KEY FINDINGS AND DISCUSSION</td>
<td>7</td>
</tr>
<tr>
<td>Issues affecting people's health and use of health services</td>
<td>7</td>
</tr>
<tr>
<td>How should we be listening to ethnic minority communities in Glasgow?</td>
<td>12</td>
</tr>
<tr>
<td>LESSONS FROM THE PROCESS</td>
<td>18</td>
</tr>
<tr>
<td>RECOMMENDATIONS</td>
<td>21</td>
</tr>
</tbody>
</table>
WHY HAVE WE BEGUN ‘LISTENING TO COMMUNITIES’?

Health service providers are well aware of the need to ensure health services are responsive to patient and community needs, with public involvement and patient focus now a key responsibility of all NHS organisations in Scotland. But within this important shift in thinking, there is also the need to recognise and celebrate the cultural diversity of our local communities, as seen in the Scottish Executive’s “Many Cultures, One Scotland” campaign.

Planning appropriately for ethnic minorities, who may experience problems or have different expectations in using services, requires health care providers to understand how they can engage effectively with these diverse communities at all stages of service planning and evaluation. Feedback from past efforts to involve local ethnic minority communities in Glasgow has also emphasised the need for greater co-ordination of consultation processes with these communities to avoid ‘consultation abuse’.

To address these issues in collaboration with local people, the Listening to Communities: Involving People in Health programme of open space events was piloted with four broad ethnic minority (EM) groups in Glasgow, sponsored by Greater Glasgow NHS Board. The events were organised and written up by the Primary Care Trust’s Community Research Officer (Multicultural Health), who received advice and support from the Trust’s Community Forum for Equality and Diversity and other community members. Our approach allowed for individual communities to firstly identify their unique health priorities and express their views on getting involved with NHS planning. An action-planning conference was then held in January 2003 with representatives from each of the communities, health service planners and other health professionals from Greater Glasgow NHS. The delegates jointly discussed the community research findings and put forward recommendations for working in partnership with ethnic minority communities across Greater Glasgow to improve health and health care.

This Summary Report offers a useful guide on how people from marginalised ethnic groups wish to be listened to and involved in shaping local health services. It promotes ways of
working which are truly collaborative and empowering, and which support positive initiatives within ethnic minority communities around health.

Dr Rafik Gardee  
Consultant in Public Health Medicine,  
Greater Glasgow Primary Care NHS Trust

Mr John Crawford,  
Principal Health Promotion Officer  
Greater Glasgow NHS Board

A copy of the full research report is available on request by contacting:

Lyndell Weaver  
Community Research Officer  
Multicultural Health Development Programme  
Greater Glasgow Primary Care Trust  
Tel: 0141 211 3898  
email: lyndell.weaver@gartnavel.glaomen.scot.nhs.uk
WHO WAS INVOLVED?

Four broad black and ethnic minority community groups were selected whose participation in NHS planning had been relatively low and for whom considerable barriers to involvement were thought to exist. It should be noted that consultations were not conducted with all of the ethnic minority communities in Glasgow and that further work with other community groups will be ongoing. The events were as follows:

<table>
<thead>
<tr>
<th>Event</th>
<th>Target Groups</th>
<th>Participant Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Listening to Asian communities 19 June 2002</td>
<td>75 to 100 people from Indian, Pakistani, Bangladeshi and other south Asian communities.</td>
<td>90+ (elderly and younger women; older men; youth; community workers)</td>
</tr>
<tr>
<td>2: Listening to African and Caribbean communities 24th August 2002</td>
<td>75 to 100 people from established African and Caribbean communities and the newer asylum seeker communities.</td>
<td>60+ (women, men, asylum seekers and refugees)</td>
</tr>
<tr>
<td>3: Listening to the Chinese community 1st October 2002</td>
<td>50 to 75 people attending existing Chinese user groups and professional people.</td>
<td>50+ (women, men, professional people, young people; community workers)</td>
</tr>
<tr>
<td>4: Listening to asylum seekers and refugees 25th October 2002</td>
<td>75 to 100 people from asylum seeker communities.</td>
<td>60+ (25 asylum seekers and refugees: Turkish, Russian, Iranian, African and others; plus community and statutory workers)</td>
</tr>
<tr>
<td>5: Listening to Communities action-planning conference 21st January 2003</td>
<td>75 representatives from each community; 75 NHS planning and other health professionals.</td>
<td>120+ (48 community representatives and voluntary sector workers; 60 health service professionals, 12 other statutory workers)</td>
</tr>
</tbody>
</table>
AIMS OF THE LISTENING TO COMMUNITIES OPEN SPACE EVENTS

Each community event had the following aims:

- to identify and explore the health priorities of the community or groups being consulted
- to identify suitable methods for involving people from the respective groups in ongoing service planning and community development around health.

The outcome of the Listening to Communities programme will be the development of a Glasgow-wide action plan for involving ethnic minority communities in NHS service development. This forms an important part of the work of promoting race equality and ensuring culturally competent services which all health organisations are now required to do under the Race Relations (Amendment) Act 2000 and the Scottish Executive Health Department policy guidance, 'Fair for All'.

The events canvassed the views of ethnic minority communities across the Greater Glasgow area. Health care and public involvement was discussed in relation to all NHS services, including:

- Primary Care
- Acute Care
- Maternity Services
- Children’s Services
WHAT WAS THE PROCESS?

The *Listening to Communities* programme was designed using a combination of 'open space' and public meeting methodology. The events had an educational component to raise awareness about the benefits of, and opportunities for, ethnic minority communities to get involved in the NHS.

Open space technique was chosen to allow the different communities to contribute to the consultation's agenda, by raising their own issues for discussion. In this way we hoped to encourage more creative thinking on the issue of public involvement and community action in relation to health and health care. An external facilitator, supported by one or more interpreters, was hired in to run the open space discussion and feedback sessions of each event. Bilingual community members, workers and group discussion guides were also employed to support and focus break-out groups. The method was adapted slightly for each event according to target group characteristics, eg. multiple language needs at the asylum seeker and refugee event required the process to be conducted in small language-based groups from start to finish.

The recorded discussion points and actions for each group were either brought together for collective voting or prioritised within the groups. Qualitative data processing was used to write up a discussion of the issues and actions raised at each event, and common themes were identified across the events.

In addition to community consultation, each event had a health promotion aspect consisting of information stalls and massage provided by Primary Care Trust staff, Social Work and community services.

To attract participants, translated promotional literature was sent to a range of local EM community groups, organisations and networks. Visits were also made to GP surgeries with high numbers of ethnic minority patients, as well as local Asian, African and Chinese businesses and religious centres to promote the events.
The findings from the *Listening to Communities* open space events fall under two broad categories:

- issues affecting ethnic minority communities' health and use of health services
- issues regarding the involvement of people from ethnic minority communities in the development of NHS services and community-led health initiatives.

Of course there is some overlap in the findings in that people sometimes raised health issues and priorities on which they would like to work together with the NHS to address.

**Issues affecting people's health and use of health services**

We found that a number of key issues and priorities regarding health and health services were important to more than one, and in some cases all, of the ethnic minority communities we consulted. In addition, issues were raised which were specific to particular ethnic backgrounds and cultures. These findings are summarised below.

**Barriers to accessing health services**

*Language and communication barriers* are experienced by first generation, elderly members of Asian and Chinese communities as well as new migrants from Asian, Chinese, African and other ethnic minority backgrounds, including many asylum seekers and refugees. Access to interpreting services remains a problem for routine GP and hospital appointments, dental and other emergencies. Telephone interpreting services for emergencies and general appointments were recommended by a group of Turkish asylum seekers. Bilingual medical
staff are generally preferred to the use of interpreters because of concerns about confidentiality and flow of communication. Verbal explanations in people’s own language are needed for health consultations, information about available services and organisational structures in the NHS and for health promotion activities, in combination with translated health information.

**Limited understanding of health services** was another access barrier identified by all the community groups and was a particular problem for isolated groups such as the elderly, new migrants and asylum seekers who are used to different health systems. There is a need to increase awareness of available health services, GP registration, appointment and referral systems, the complaints system and differences in the roles of professionals. Some asylum seekers reported problems of orientation: knowing where local GPs and hospitals are situated and how to get there by public transport.

Other identified access barriers for the Asian community included lack of transport and childcare. For asylum seekers, GP surgeries taking asylum seeker patients were often located at a great distance from people’s homes.

**Health promotion needs**

The need for stronger *preventative health work within communities* was an important priority for all groups. Asian, African and Caribbean and asylum seeker groups indicated there was a need for more written information in their community languages. Older Asian participants gave preference to audio-visual information such as videos and group education sessions with bilingual workers. Chinese participants noted that more guidance was needed on how to access existing health information resources. There is currently very little health promotion material available in languages spoken by asylum seekers and refugees. It was suggested that more peer education could take place utilising people from within particular asylum seeker and refugee communities.

*Health information needs of Asian community:* cancer, breast screening, asthma, mental health, diabetes, youth health issues, arthritis and alternative treatments, eg. herbal
remedies, Alexander technique; side effects of medication and multi-medicine taking, injections, exercise and healthy eating, diet and Ramadan. Specific groups should be formed to target men and cancer, women’s health, parents etc.

*Health information needs of African and Caribbean communities*: sickle cell disease, skin conditions, male circumcision, female circumcision (Somali women), cancer, diabetes, heart problems, lung problems, how to feed and dress children and heat flats appropriately (newly arrived families).

*Health information needs of asylum seekers groups*: sexual health information, diseases and conditions suffered on arrival in Scotland, and information about available health services.

**Culturally specific needs and expectations of health care**

The provision of culturally sensitive health services was important to all four community groupings, although each group had specific needs and expectations in this regard. The provision of *prayer facilities* (rooms, signage and wash jugs for ablutions) and Halal *catering* in hospitals were important requirements for Asian Muslim participants. Culturally appropriate catering was also raised by African and Caribbean participants who felt this would be healing and beneficial for in-patients.

Providing *free inoculations for travel* was a high priority for both the Asian and the African and Caribbean communities. Participants noted that many people were not taking anti-malaria tablets because of the cost involved and returning to Scotland with malaria. One group pointed out that treatment for malaria costs the NHS more than it would to provide an NHS prescription for prevention. Given that different GP practices and Health Boards have different protocols for funding vaccines and travel clinics, this a complex issue which may require further lobbying by concerned medics and community members.

Increasing *expertise in tropical medicine* in the NHS, and specifically knowledge of African diseases, was the top priority for the African and Caribbean event and was also raised by participants at the asylum seeker and refugee event.
The Asian event (with a majority of elderly participants) gave a strong priority to the provision of complementary medicine, specifically *aromatherapy services for the elderly*, within the NHS.

Similarly, the Chinese community were concerned about improving access to *traditional Chinese medicine* (TCM) and gave a strong priority to introducing TCM clinics within NHS health centres. Improving staff awareness about Chinese *cultural beliefs and practices* related to childbirth was also raised by a non-Chinese midwife.

A need for understanding about the practice of *male circumcision* was raised by two groups at the African and Caribbean event. Awareness of *female circumcision*, information for Somali women on this and a clear policy on treatment of women who have been circumcised were also raised by one participant at the asylum seeker event.

**Need for staff training**

The *training of NHS staff in cultural awareness* was promoted by participants at all the events. Chinese and African and Caribbean participants suggested that community people could be involved in designing and/or delivering this training. It was recommended that the following areas be covered:

- the provision of culturally appropriate food (Asian event; African and Caribbean event)
- the religious requirements of Muslim patients such as use of prayer facilities (Asian event)
- cultural beliefs and health care needs of Chinese patients, made relevant to the health professionals concerned (Chinese event)
- awareness of discrimination (Chinese event)
- importance of cultural practices such as circumcision (African and asylum seeker events)
Increasing **knowledge of tropical diseases and conditions** in the NHS through training was also raised by several African groups, including asylum seekers and refugees. Involving African experts in tropical medicine in staff training was strongly recommended.

Providing information and education to GPs on **youth health issues**, communication and the cultural issues and worries facing young people was a priority for young Asian participants.

**Recruitment of medical and health promotion staff from ethnic minority backgrounds**

A preference for being seen by bilingual staff from a similar cultural background to the patient was evident among all four community groups. Employing more qualified individuals from the respective communities was seen a solution to the language and cultural barriers people experienced in accessing NHS services and information about health issues. Asians, African, Caribbean, Chinese participants and several refugee groups all called for the recruitment and retention of more doctors, nurses counsellors, psychiatrists, clinical psychologists, health promotion and advocacy workers from their own communities. Involving specialists in tropical medicine and health promotion officers from African backgrounds were of particular importance to participants at the African and Caribbean event.

The recruitment of staff from ethnic minority backgrounds was also considered the most important way in which people from all these communities could increase their influence on the delivery and development of health services in Glasgow.

**Improving community integration**

Another key issue for asylum seekers and refugees was addressing problems of social isolation and the mental health implications of this. Actions proposed to improve the integration of newcomers to Glasgow included producing a combined directory of health, leisure and other community services; providing free leisure activities and more befriending schemes for asylum seekers and refugees. Tackling racism was another important concern.
How should we be listening to ethnic minority communities in Glasgow?

Community event participants and delegates at the action-planning conference all made important contributions to the specific question of how NHS Greater Glasgow should be involving ethnic minority communities and building their capacity to influence planning processes. Also discussed were the ways in which the NHS could support community-led activities around health.

**Giving all ethnic minority communities an equal voice** - There was evidence of a perception among minority groups within Glasgow’s ethnic minority communities, that their cultural and health needs were often overlooked in ‘multicultural health’ research and NHS service planning. All endeavours to involve and represent local communities should acknowledge and give equal consideration to the diverse ethnic groups living in Glasgow. This approach was considered a strength of the *Listening to Communities* open space events, even though more work was needed to ensure the involvement of every ethnic minority group.

**Community development staff** - It was argued that qualified professionals from ethnic minority backgrounds could have a role in involving local people and supporting community development work around health. Participants at the African and Caribbean and Chinese events suggested that Health Promotion Officers be employed who have a community development function and liaise with existing community organisations to target health information accurately. The information needs of isolated and vulnerable groups, such as the elderly, were of particular concern. Other groups at the Chinese event and action-planning conference recommended there be a named person at each LHCC (preferably bilingual) and the Health Board to develop work in partnership with ethnic minority community organisations in response to their health needs. These staff would require relevant background knowledge and training to work with EM communities.

**Working with existing ethnic minority organisations** - It was felt by many participants that working with existing Asian, African, Caribbean, Chinese and refugee community organisations was one of the best ways of identifying and addressing local communities’
needs. However it was also recognised that these organisations themselves needed to garner more participation from their constituencies and that more volunteer groups were needed.

Community forums and representation on planning groups - The model of a community forum representing BEM communities was discussed as a way of involving people in planning, but problems of inadequate representation and influence were raised, specifically in relation to the NHS Board's Ethnic Minority Health Advisory Committee. According to participants at the African and Caribbean event and the conference, an effective forum would be representative of and "encouraging for all ethnic minority communities". It would have a budget for liaison and consultation with wider communities and a feedback mechanism by which the NHS were accountable to the forum's recommendations. For example, it was suggested that forum members be invited to attend Board meetings and vice versa. Building the capacity of EHMAC would also require giving members more information on the workings of the Board and training to carry out their new responsibilities.

The creation of representative forums was also suggested for LHCCs, as were regular meetings with particular population groups, such as asylum seekers and refugees. These would allow for local primary care services to fully understand the problems and needs facing these communities and should inform LHCC Development plans.

Multi-agency advisory committees which include community members is another inclusive model for working on specific resources or treatment protocols. One of the least consulted groups, asylum seekers and refugees expressed a desire for increased representation on policy-making and planning groups. Given the overlapping nature of many of the needs of asylum seekers (e.g. mental health and social isolation), it makes sense that the NHS should work in partnership with other agencies such as Social Work, Education and voluntary organisations.

Patient Feedback And Community Needs Assessments - Other ways of involving people suggested by Listening to Communities were independently conducted patient feedback studies to monitor the quality of GP and hospital services and needs assessments of individual community groups (Chinese, etc).
Large group consultation processes - Evidence from the asylum seeker event suggests that large group processes such as open space events are a good way of raising awareness about NHS services and developments. However as a method of public involvement, they are perhaps not suited to very diverse groups who do not identify as a “community” and for whom political and cultural tensions may prevent collective participation.

Building the capacity of ethnic minority communities

Perhaps the most salient finding with respect to involving ethnic minority communities was the need to **empower and equip people to get involved** in health improvement and service change. In the first place there is clearly a need for improved communication to new and isolated ethnic minority groups, such as asylum seekers, about the organisation of services and how to access them. Information about existing opportunities for participation in the NHS could be included in communications about services or health promotion activities.

As one participant put it, newcomers and isolated groups “**need to know who to approach to influence change.**” (G12, Asylum Seeker event). This would involve explaining to community groups (preferably in person, using bilingual workers or interpreters) about organisational structures such as LHCCs. There is also the need to raise the profiles of existing patient groups and public involvement structures across the NHS, explaining their function.

Participants also felt that people needed to develop **community action skills** to be involved effectively with NHS services. For the long-term, the Chinese community suggested the NHS develop targeted programmes in schools (in partnership with other organisations) to encourage young people into careers in health and community development.

Secondly, there is evidently a need to overcome **barriers to people’s involvement**. This means raising awareness across the NHS regarding the lifestyles of local ethnic minority people; setting meetings and consultations at appropriate times (e.g. not on Friday, a Muslim prayer day) or using alternative means of gathering views (e.g. translated questionnaires) for groups with long working hours (e.g. Chinese). Providing child care, interpreting services and covering individuals’ transport costs were strongly recommended by participants, as was
payment of community representatives who have an ongoing role in planning. In the long term development of relationships with EM groups, it was suggested the NHS provide opportunities and incentives for staff to learn community languages.

Asylum seekers and refugees in particular need more *encouragement to participate* in NHS planning processes, given their past trauma and mistreatment and the suspicion of authority likely to result from this. This could be achieved through targeted visits to community groups, explaining the importance and purpose of consultation activities.

Given that *ethnic minority carers* are likely to be more isolated and their free time especially limited, the NHS and community-based organisations need to “go to them”. This approach would mean targeting information about involvement opportunities via respite services, outpatients departments, befrienders and other staff. Because of their extra costs in care arrangements, remuneration for carers' time was also seen as essential for involving this group.

Increasing *understanding of NHS complaints systems* was another important need for building the capacity of ethnic minority communities. Many participants were aware that they had a right to have their say on services in this way but did not know how to go about it. It was noted at the conference that complaints procedures are currently inaccessible to many community groups and need to be refined with language links.

**Involving communities around their priorities/community development**

The Listening to Communities participants also identified ways in which they would like to be involved in addressing some of the common health issues and priorities for their communities (as described on pages 3 to 6). These findings are summarised below.

**Recruitment** - It was recommended that an observer group of ethnic minority community members be created to support people from EM groups responding to NHS recruitment schemes.
Involvement in health promotion work - It was thought imperative that Health Promotion have a consultative strategy, whereby ethnic minority groups were involved in the identification and production of information around specific topics. A translated information pack about available health services was also suggested which would outline what NHS services expect of patients, and issues specific to using services for different EM communities. The use of peer education was also recommended whereby, for instance, refugees are employed to contribute to health promotion activities in community settings.

Ensuring culturally sensitive services - Communities also wished to be involved in ensuring the provision of culturally sensitive services. This should be done by involving people from ethnic minority communities in a) the planning stages of new services, b) proposals for service revamping and c) evaluation of services. To support this, measures such as the Performance Assessment Framework should be adapted to include race equality / cultural competence in service provision. Resources need to be ring-fenced by NHS organisations to do this.

Involvement in cultural awareness training - The scope for involving EM communities in cultural awareness training of staff should also be considered by NHS organisations in Glasgow. In addition to seeking out qualified representatives from all the diverse EM groups (for instance, Chinese representatives have not contributed to such training to date), cultural awareness courses should be provided on the basis of a staff training needs analysis, which is itself based on the areas of need identified by communities (these are described earlier).

Involvement in research - Community-led research was another identified means of involving EM communities in health. Specifically, it was a priority that paid community representatives be pro-actively sought to help develop research into tropical diseases and conditions suffered on arrival in the UK.

Improving community integration - Furthering health and wellbeing through improving the integration of asylum seekers and other newcomers in Glasgow was another priority which could be addressed through the provision of a resource centre to enable access to local services. This would be accompanied by a combined, all-inclusive directory of available services (health, leisure and social services, community groups).
Support for existing community organisations and new initiatives - All of the communities consulted asked that the NHS give more support to the work of existing community organisations, groups and charities in terms of funding and health promotion materials, eg. a Sickle Cell and Thalassaemia Awareness charity asked for television campaigns on this topic to be produced by Health Promotion. There was clearly a need for NHS Greater Glasgow to provide more information about its available small grant schemes to ethnic minority organisations. More funds might also be directed into such schemes to support community-led activities around ethnic minority health.

Other ideas requiring support and development included:

- an action group on malaria and tropical diseases which would involve health professionals with a special interest in tropical medicine and community representatives.
- self-help groups for asylum seekers from similar backgrounds to discuss their experiences / mental health problems
- a social / support group for Turkish women
- counselling support directly following birth-giving for women from Asian communities to detect and address post-natal depression, as this issue, like other mental health issues, goes largely unrecognised within the communities.
LESSONS FROM THE PROCESS

Conducting the *Listening to Communities* events was itself a learning experience on how to consult with local ethnic minority communities. It did prove to be overly ambitious to run a programme of consultation events with several diverse communities over a period of months with only very limited staffing. We found that the same techniques of recruitment and consultation could not simply be applied again to different community groups, and that some groups needed more groundwork to encourage attendance than others.

It was important to involve community members in the organisation of these events. However the publicity, organisation and follow-up work of supporting individuals who want to be further involved really requires a solid team of support staff, especially if the views of isolated groups like asylum seekers or gypsy travellers are being sought. Sending out literature alone will not bring such people to an event; having the time and staff for personal visits to community centres and street/outreach work is far more effective in engaging people through establishing relationships.

It is also important to have a research team to help process and/or verify the qualitative processing of large amounts of data.

Many participants appreciated that NHS Greater Glasgow had consulted their respective communities individually prior to organising a multi-ethnic event. Remarks were made to the effect that this was the first time African and Caribbean people in Glasgow had been recognised as a distinct ethnic minority community by the NHS. The process allowed for the identification of ethnic- and culturally-specific needs as well as areas of common need across ethnic minority groups.

There were some problems in maintaining a focus on the theme of the events. This may have been due to varying target groups and levels of knowledge about health services, as well as facilitation and communication issues and the nature of the ‘open space’ method. As a result, many people perceived the events as consultations about the quality of health
services *per se*, rather than as consultations on what should be done across NHS Greater Glasgow to involve their communities in service planning. This meant that discussions largely focussed on health needs and what should be improved in health services with sometimes very little discussion of how people from these communities could be involved in processes of service improvement.

In hindsight it may have been better to present and consult on specific models or examples of public involvement, asking ethnic minority communities their views and preferred options, rather than using open space technique, which asks people to set their own agendas and related actions. Even so, the action-planning conference gave an opportunity to look at how the NHS could involve EM groups around their identified priorities, and this was perhaps a more meaningful and innovative approach to issues of public involvement.

It is also possible that the concept of empowering communities to set long-term goals for promoting their own health is still a new one for many people, and that an expectation on NHS services to simply provide what is best for everyone is more the norm. But it is also true that for some participants, particularly asylum seekers and refugees, being involved in NHS service development was a new concept, while their understanding of available health services was very limited. Given the opportunity to voice their views, their contributions tended to be much more about needs and problems they faced in using local health services.

For other participants there was a strong scepticism that ‘involving’ their communities had happened many times before but had not led to significant change in health services. Certainly these perceptions, which are often based on past experiences of ineffectual consultation and lack of feedback, are one of the barriers which the health service faces in engaging with people from ethnic minority and other communities. Managing people’s expectations is a consideration for any consultation activity. While the sponsors may have the best intentions of taking issues forward, it is important that a representative is present throughout the event to hear what is being said and respond at the end in terms of what will happen to people’s contributions. It is even better practice for the sponsor to respond with information about current systems or constraints within the NHS which may prevent certain recommendations being implemented. This point was made clearly by a participant at the
African and Caribbean event: "More information should be given to points about funds and facilities available, so [the consultation] will be used more wisely."

We also found that the open space events were not well suited to discussing sensitive health issues with attached stigma, such as drug use. Unless groups were self-selectedly of one age group or gender, people notably did not openly discuss these issues. It is likely that using interviews or focus groups with asylum seekers from similar cultures, gender and age would have yielded more in-depth results. Participants at the African and Caribbean, Chinese and asylum seeker and refugee events did however favour having more large (open space) consultations, indicating that it was a positive step to target their specific ethnic groups.

Another lesson learnt in conducting the Listening to Communities events was that group facilitators may not always be equipped to answer the questions put to them by ethnic minority participants about health problems and available services. Depending on the target group, people may attend a consultation on the understanding it is a health information day and expect to receive help from health professionals. For this reason it was well-placed to include a health promotion element at the Listening to Communities events.
RECOMMENDATIONS

The *Listening to Communities* programme of consultations has led to the following recommendations for involving, listening to and supporting Glasgow’s ethnic minority communities in improving health and planning NHS services.

PRACTICES FOR WORKING WITH ETHNIC MINORITY COMMUNITIES

1. All endeavours by NHS Greater Glasgow to involve ethnic minority communities in service planning should give equal consideration to the diverse ethnic groups living in Glasgow.

2. A sea change should be effected in NHS planning processes from a culture of consulting ethnic minority communities on service changes and developments in the late stages to involving representatives from these communities at every stage/level of service planning, that is at Scottish Executive, Health Board and Trust levels.

Health Promotion Officers

3. The roles and remits of Health Promotion Officers should be clearly defined in order to cover the health promotion and community development needs of these distinct ethnic groups.

Community development staff

4. Community Development Officers (CDOs) should be employed at NHS Board and LHCC levels to work in partnership with ethnic minority community organisations to further consult on specific services and include the needs of local communities in action planning.
Community development staff, including Public Health Practitioners and any other interested health professionals, should be given training in good practice for involving and working with ethnic minority communities.

CDOs should support and help develop the health-related initiatives of local communities such as self-help groups and research priorities.

CDOs should co-ordinate regular meetings with representatives from local ethnic minority communities and asylum seeker groups to inform LHCC development plans.

Ethnic minority community organisations

Ethnic minority community organisations should work with LHCCs and Trusts to promote ongoing opportunities for participation in the NHS among their constituencies.

Representative ethnic minority community forum

One forum of ethnic minority community members should exist at NHS Board level which is open to and representative of Glasgow's diverse ethnic minority groups, including asylum seekers. This requires a review of membership of existing ethnic minority forums.

The capacity of this forum should be built through providing extensive information on the workings of the Board and training for community representatives (see Recommendation 21).

Forum members should be responsible for liaising and consulting with their constituencies about specific Health Board policies and service developments and presenting the findings at meetings.
The forum should be further involved in Board decision-making through inviting a member/s to attend Board meetings and inviting Board members to attend forum meetings.

A feedback mechanism should be created by which the NHS Board is accountable to the advice of the forum.

A budget should be allocated to the forum to allow for wider consultation and involvement of ethnic minority communities in Board decision-making.

**Community needs assessments and patient feedback**

Primary, secondary and tertiary care services should routinely outsource independent patient feedback studies which include ethnic minority communities. This information should be used to monitor and improve the quality of GP, hospital and specialist services.

Needs assessments of individual ethnic minority groups (Asian, Chinese, African, Caribbean, asylum seekers and refugees) should be conducted at local and city-wide levels and used to inform service development (as also recommended by *Fair for All*).

**Large group consultation processes**

Large group processes such as open space events should be used in needs assessments and priority-setting by ethnic minority communities. Discussion of sensitive health issues, service models or resources should be conducted via gender- and age-specific focus groups, personal interviews or questionnaires.
BUILDING THE CAPACITY OF ETHNIC MINORITY COMMUNITIES

Promoting opportunities for ethnic minority community involvement

18 Once a co-ordinated strategy for involving and supporting ethnic minorities in health action is agreed (based on the above recommendations), communications strategies should be commissioned by the NHS Board, targeting ethnic minority communities to give people opportunities to be involved in different strands of NHS Greater Glasgow. Religious centres, radio stations and English classes should be targeted. Communications should also raise the profiles of existing patient / community groups in which people from ethnic minority and asylum seekers groups might play a role.

19 The involvement of asylum seekers and refugees in NHS planning processes should be further encouraged through targeted visits to community groups by development workers or health visitors, explaining the importance and purpose of public involvement activities.

20 NHS planning groups should ensure the involvement of carers from ethnic minority communities by advertising public involvement activities via respite services, outpatients departments, befrienders and other staff in touch with carers.

Training of community representatives

21 People who are recruited to ongoing planning groups and forums should be given training in community action skills (representing community views, negotiating and influencing) and the structure and function of NHS organisations such as LHCCs.

School education programmes

22 Targeted programmes should be developed in schools to encourage young people from ethnic minority communities into careers in health and community development. The NHS should develop such programmes in partnership with relevant EM voluntary/community organisations.
Addressing barriers to involvement

23 Understanding should be developed across the NHS to ensure that consultation activities are timed and geared to suit the lifestyles of local ethnic minority communities. Information pertaining to lifestyles and culturally appropriate involvement could be a part of cultural awareness training for NHS staff (see Recommendation 34).

24 Finances should be allocated at all public involvement activities to cover people's transport costs.

25 Where necessary, child care should be provided at consultation and planning activities to encourage the involvement of women.

26 Where appropriate, interpreting services should be provided to allow the full involvement of people from ethnic minority communities.

Complaints procedures

27 Complaints procedures should be reviewed and revised to make them more accessible to service users from ethnic minority communities.

IN Volving communities around their priorities

Community Involvement in NHS Staff Recruitment

28 An observer group of representatives from Chinese, Asian, African and Caribbean and refugee groups should be created to support and build the confidence of people from EM backgrounds in applying for NHS positions. This should be supported by targeted recruitment campaigns to promote employment opportunities to ethnic minority communities.
Community involvement in health promotion

29 A consultative strategy should exist in the production of all health promotion materials for ethnic minority communities, whereby people from these communities are consulted on the content, accessibility and format of materials.

30 New health promotion materials for these population groups should in part be developed according to the priorities for awareness-raising identified by Listening to Communities, or other community-based research. The LTC priorities include sickle cell and thalassaemia, cancer, diabetes, mental health, cardiovascular problems, sexual health, child health, health conditions suffered on arrival in Scotland.

31 Service users from ethnic minority communities should be involved as peer educators in health promotion activities, particularly around topics with attached stigma.

Community involvement in NHS communications about services

32 An information pack about NHS services should be produced as literature, audio or video in different languages with the involvement of ethnic minority community representatives. The pack should contain:

a) basic information about available services
b) expectations of the patient by the NHS
c) expectations of the NHS by the patient
d) issues specific to use of NHS services for different communities
e) information on complaints procedures

Community involvement in ensuring culturally sensitive services

33 Ethnic minority communities should be involved in a) the planning stages of new services, b) consultations for service revamping and c) evaluation of services to ensure the provision of culturally sensitive facilities, including catering and places for worship (as identified by the LTC findings). Resources for this consultation about services should be ring-fenced.
Community involvement in cultural awareness and race equality training

34 A staff training needs analysis should be conducted across NHS Greater Glasgow such that programmes of cultural awareness and race equality training are developed which cater to the professional needs of staff as well as the priority areas identified by local ethnic minority communities (as described in LTC report).

35 Representatives from established Asian, African, Caribbean, Chinese communities and the newer refugee groups in Glasgow who have skills in training should be involved in the design and delivery of cultural awareness training to frontline staff of all NHS Greater Glasgow organisations.

Community-led research

36 Community representatives should be involved in the identification and design of NHS-commissioned scientific research which is relevant to ethnic minority communities. This should include research into tropical diseases and conditions suffered by newcomers to Scotland.

37 Where resources are available, community representatives should be remunerated for their input in this capacity.

Jointed up communication about services to asylum seekers and refugees

38 To improve the integration of asylum seekers and other newcomers in Glasgow, an all-inclusive directory of health, education, leisure and social services, public transport and community groups should be produced, combining existing directories. This should be administered by a centre of staff who can assist people in accessing available services.

Support health initiatives of ethnic minority community groups

39 The NHS Board, all Trusts and LHCCs should provide resources and designated staff time to develop and support local issue-based charities and self-help groups within
ethnic minority communities, based on the priorities identified by LTC. These included a sickle cell and thalassaemia awareness group; an action group on treatment and prevention of malaria and other tropical diseases\(^1\); a group supporting asylum seekers coping with mental health problems.

\(^1\) One of functions of this group would be lobbying of the Scottish Executive Health Department about costs of prescriptions for travel inoculations.