

**Consultation with  
'Traditionally Under  
Represented' Groups on the  
Healthcare for London  
Proposals  
28th March 2008  
*Summary***



  
*Strengthening public influence on health*

62, Beechwood Rd.  
London E8 3DY  
0207 254 1582  
[www.health-link.org.uk](http://www.health-link.org.uk)

**We would like to thank all the individuals who gave their time to participate in this consultation and the following organisations who facilitated our contact with them:**

1. Action Disability Kensington and Chelsea (ADKC)
2. Age Concern Tower Hamlets
3. Alzheimer's Society Enfield Branch
4. Alcohol Recovery Project (ARP)
5. British Thyroid Foundation
6. Camden Chinese Community Centre
7. Camden Lesbian, Gay, Bisexual Transgender (LGBT)Forum
8. Carers UK
9. Chase Farm Mental Health Unit (Barnet, Enfield & Haringey Mental Health Trust)
10. Day Mer Turkish and Kurdish Community Centre
11. East London Rastafarian Information & Community Services
12. Hackney Libraries Housebound Readers Service
13. Hammersmith and Fulham Refugee Forum
14. Haringey Libraries Special Needs Children's Reading Group
15. Heston House Care Home
16. Her Majesty's Prison Wandsworth
17. International Buddhist Progress Society
18. League of Jewish Women
19. Lohana Social Centre
20. National Association for the Care and Resettlement of Offenders (NACRO)
21. Queens Park Bangladeshi Association
22. Ramgarhia Sikh Association
23. St. Ann's Hospital (Barnet, Enfield & Haringey Mental Health Trust)
24. St Barnabas
25. St Joseph's Hospice
26. St Raphael's
27. St Mungo's, Seven Sisters Road
28. Saheli Enfield Branch
29. Salmon Youth Centre
30. Southwark Travellers Action Group
31. Sutton Mental Health Action Group
32. Terrence Higgins Trust
33. The Shanti Centre
34. United Reform Church
35. United Reform Church Children's Group
36. Walthamstow Deaf Club

Health Link's Patient and Public Involvement Network whose members facilitated contact for us with groups via their Community Connections

Ray Phillips, Kathy Johnson and Sue Duffy of the Kings Fund who used the Patient and Public Involvement Specialist Library maintained by the Kings Fund for the National Electronic Library for Health ([www.library.nhs.uk/ppi](http://www.library.nhs.uk/ppi)) to undertake a literature search for us.

Library staff at Hackney and Haringey library services who facilitated contact for us with frail older people living at home, hospice patients and children with special needs.

## 1. Executive Summary

Health Link was commissioned by the London PCTs to undertake outreach consultation with groups of people seen as traditionally under represented in public consultations, on *Healthcare for London: Consulting the Capital*. This work was supplementary to the local consultation carried out by the London PCTs and to a pan-London survey by Ipsos MORI. We had developed a list of potentially under-represented groups and undertook a literature search to validate this list. Many of these groups suffer significant health inequalities and therefore have a higher stake in the decisions made as a result of the consultation than those who do not suffer such inequalities. This in itself justifies dedicated outreach work to obtain their views, even if the assumptions about their disengagement were not to be borne out.

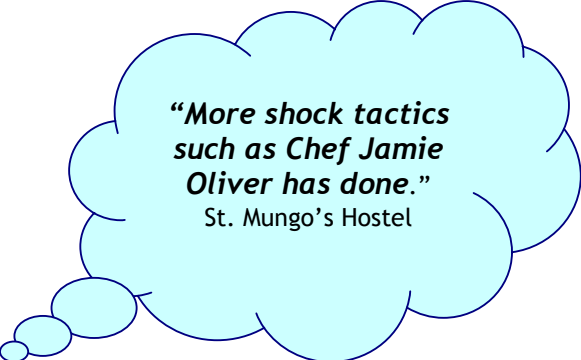
In all, 36 meetings were held with a total of 317 people. 284 completed a demographic form and the remaining 33 chose not to do so. Of those who completed a demographic form, the following identified themselves against the categories of people (in many cases more than one category) whom we were targeting as traditionally under represented:

TABLE ONE-NUMBERS SELF REPORTING BY CATEGORY					
CATEGORY		NO.	CATEGORY		NO.
Males (where completed)		123	Females (where completed)		168
Employed	50	Unemployed	75	Retired	91
Alcohol Dependence		30	Mental health service use(outpatient)		22
Carer		17	Non White Ethnic Minority		121
Child		19	Offender		13
Child with special needs		8	Older person		82
Dementia		23	Older frail person living alone		16
Drug Dependence		16	Physical disability		41
HIV positive		14	Prisoner		7
Homelessness		11	Refugee or asylum seeker		10
Hospice patient		11	Religion or belief		177
Learning disability		30	Resident in a care home		30
Lesbian, gay, bisexual, transgender		17	Sensory impaired		18
Living on a low income		72	Traveller		11
Long term medical condition		92	Woman		168
Mental health service use (Inpatient)		10	Young person		19
NON WHITE ETHNIC MINORITY			RELIGION OR BELIEF		
<i>Asian other</i>		2	<i>Buddhist</i>		9
<i>Bangladeshi</i>		8	<i>Christian</i>		90
<i>Black African</i>		24	<i>Hindu</i>		32
<i>Black Caribbean</i>		24	<i>Jewish</i>		11
<i>Black other</i>		10	<i>Muslim</i>		21
<i>Chinese</i>		18	<i>Rastafarian</i>		5
<i>Indian</i>		44	<i>Sikh</i>		9
<i>Pakistani</i>		3			

The localities of the organisations where we held meetings covered 18 boroughs and a range of deprivation codes<sup>1</sup> from 2 (the most deprived) to 234 (the least deprived). Although a great deal of intensive work was needed to procure the meetings in the first place, the responses received were detailed and comprehensive and of the 187 who completed evaluation forms (from 25 organisations), 90% found it as easy or easier than they expected to contribute to the meeting and 95% said they would be willing to be involved in the future. This ‘consultation capital’ can be used by the London PCTs to continue involvement and consultation on the Healthcare for London plans.


Overall, there was broad support for the general approach with reservations about the consequences of applying the model locally and where funding might come from. Some suggested that current problems need to be addressed before embarking on such a major review. A significant barrier mentioned by many participants in considering the proposals were the variables in terms of location of any new services, the ease or difficulty of travelling to them and what would happen to existing services.

**1.1 Staying Healthy:** the participants had a number of ideas about what would help them stay healthy, including help with weight loss, healthy cooking classes, free gym membership for older people and those on low incomes and compulsory exercise for children. More information that is more readily available in the community, especially about medication, was also considered important as were general quality improvements in healthcare. It was notable that some of the suggestions about new services are already supposed to exist, such as regular check ups for older people and medication reviews.




***“More shock tactics such as Chef Jamie Oliver has done.”***  
St. Mungo’s Hostel

**1.2 Maternity and Newborn care:** there was support for a choice of place of birth. Giving birth in a midwife-led unit with a doctor-led unit on the same site was the factor most frequently selected as important. There was some support for home birth, providing the home was assessed as suitable and the mother considered the possibility of complications carefully with the professionals. Help and support for young mothers was cited as an important enhancement to maternity care. The vast majority of participants who discussed this issue felt that the midwife should travel to visit the woman and not the other way round. Reasons cited for this included checking that all was well at home and spotting women at risk of postnatal depression more easily.



***“It is important to see how someone lives at home so the midwife should go there”***  
British Thyroid Foundation

**1.3 Specialist care for children:** views on concentration of specialist services for children were mixed, with recognition of the prime importance of high quality care for



***“If you have more than one child you can’t leave the others.”***  
Alcohol Recovery Project

children but worries about time taken to travel further in an emergency, the complications for families with other children of travelling greater distances and the stress this would induce, especially for disabled parents. Children in the consultation worried about the unfamiliarity of more distant locations and there was a view that children with mental health needs were better seen locally. Stabilisation of the patient by specialist staff prior to transfer, support for parents with travel and car parking, and good parent accommodation were all cited as important factors for successfully implementing such proposals.

**1.4 Mental Health:** there was some support for direct payments but also confusion about what they could be used for. Pathways of care were broadly welcomed so long as they did not enable police and social services to ‘dump’ people onto mental health services. There was strong and universal support for talking therapies with many participants outlining the difference this would make to them. The shortcomings of mental health services were also described and concerns expressed about the vulnerability of these services to cuts when funding was required for other services.

*“Loneliness is major issue and sometimes all you need is someone to listen to you”*

Enfield Inpatient MH Unit

**1.5 Urgent Care Telephone Service:** whilst there was support for this idea, many questioned whether it would duplicate NHS Direct. Participants saw value in the ease and convenience of getting advice on how to treat illness (particularly for parents of young children) and making the GP appointments system more accessible if it could be done over the telephone. Others felt this would be ‘just another pressing buttons nightmare’ and did not feel a telephone service was any substitute

*“There are phone boxes and phones here so I could use the service.”*

St. Mungo’s Hostel

for face to face contact. If such a service was introduced, it would have to be offered in languages other than English and be staffed by real people who were properly and sensitively trained, and answered promptly. Publicity would be needed so people knew about the service and what it offered.

**1.6 Specialist care for stroke, trauma and complex surgery:** this proposal attracted a mixed response with many seeing the value of the idea but expressing strong reservations. Some participants made it clear that they opposed any hospital closures if this might be the result. The majority recognised the advantages of concentrating specialist equipment for quality of care but they were also concerned that this would reduce access to such care for patients. It was felt that longer travel time for patients in need of urgent care could compromise their recovery. The extra travel for visitors was also seen as a major barrier because older or disabled people might not be able to make such

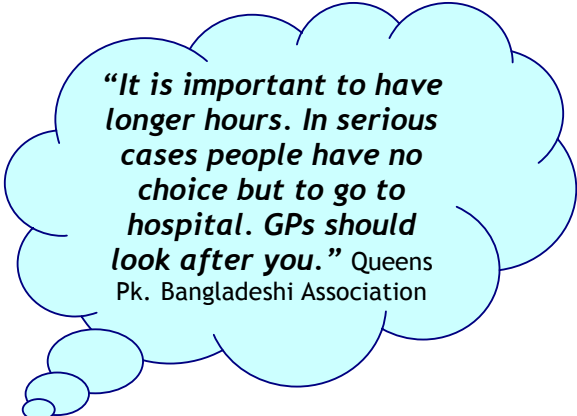
*“They have to be able to get to a hospital quickly. You could die if you don’t get there quick enough.”*

Alcohol Recovery Project

journeys. Patients would need their family close by. Not knowing the actual proposed location made consideration of the question difficult. The selection of the sites should take into account the requirements of those with the greatest needs. A lot depended on the skills of the paramedics in deciding where to take the patient and there was some scepticism about their ability to do this. In some cases, participants considered that local services should be improved to provide the right standard of care instead. Would the concentration of services in the way proposed mean local services would deteriorate? Questions were raised about whether or not these proposals would make waiting times for appointments generally better, as more patients would be going elsewhere.

### 1.7 Extended GP Opening Hours in the evenings and at weekends:

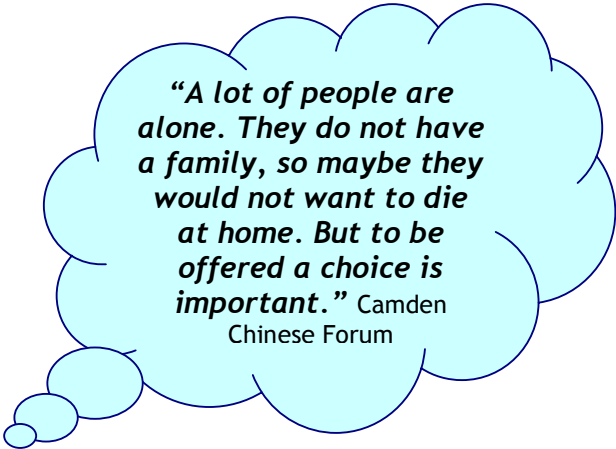
this was the proposal on which there was most unanimity, with most participants supporting the idea. Participants resented having to take time off work or, in the case of children miss school, to attend their GP and it was felt that GPs were paid enough to provide a more accessible service. Even those who did not work supported this proposal, as such a change would help them because they



***“It is important to have longer hours. In serious cases people have no choice but to go to hospital. GPs should look after you.”*** Queens  
Pk. Bangladeshi Association

are dependent on employed relatives to take them to the surgery or, for some, provide interpreting during the consultation. Patients would be able to access appointments more easily if the overall number of appointments were increased through longer opening hours. A minority of participants were concerned that if each GP worked longer hours, this would compromise the quality of their work and therefore the quality of care.

**1.8 End of Life Care:** the proposal of offering a choice of where to die attracted strong support, although there were concerns about balancing the needs of the relatives and the patient in the decision. The provision of more hospice places and adequately funded, skilled 24 hour support for relatives were key success factors. Questions arose as to whether the cost of this service would be free to the patient or treated as social care and therefore charged for. The idea of a

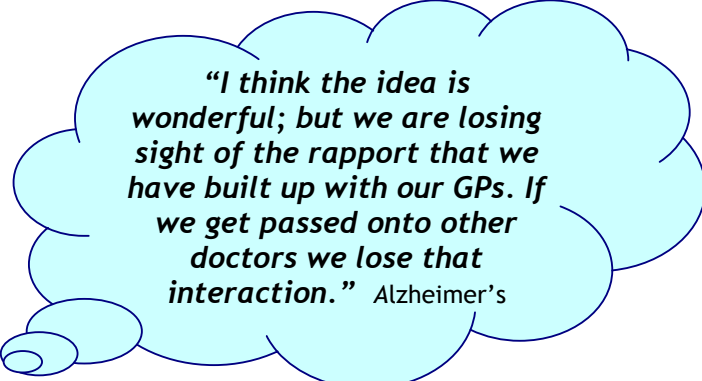


***“A lot of people are alone. They do not have a family, so maybe they would not want to die at home. But to be offered a choice is important.”*** Camden  
Chinese Forum

single provider to coordinate care at the end of life was broadly welcomed. Some questioned whether this should not already be provided by the GP, who was a known person for the family and patient at a time of great distress. Such a service would have to be easy to access, adequately funded and sensitive to cultural and language needs.

**1.9 Polyclinics:** there was strong support for this model but participants found it difficult to conclude that it would work well in practice because they could not be clear on the location. Some considered the 1.5 mile distance for most Londoners cited in the consultation document as too far, especially for older or disabled people.


Another strong reservation related to the loss of the relationship with the GP, where this was good. Subject to these reservations, advantages cited included better access and convenience, greater flexibility in appointments and more accountable GPs. Participants were concerned that this complex service should be well managed and given stable funding, not subject to cuts if a PCT went into deficit. Travel concerns were the overriding issue including time, convenience and cost.



***“I think the idea is wonderful; but we are losing sight of the rapport that we have built up with our GPs. If we get passed onto other doctors we lose that interaction.”*** Alzheimer’s

Views on whether GPs should move to a polyclinic depended on participants’ current experience of GPs and the accessibility of surgeries. The majority thought that all GPs should be networked to a polyclinic. Any other approach would lead to inequality. Participants were clear that the decision on which GP surgeries should move must not be left to GPs but should be carefully planned and involve the local community. Most participants agreed with the services suggested for inclusion in polyclinics, except that here were mixed views on including social services and leisure services. Many suggestions were also made for other services which could usefully be located in the polyclinics.

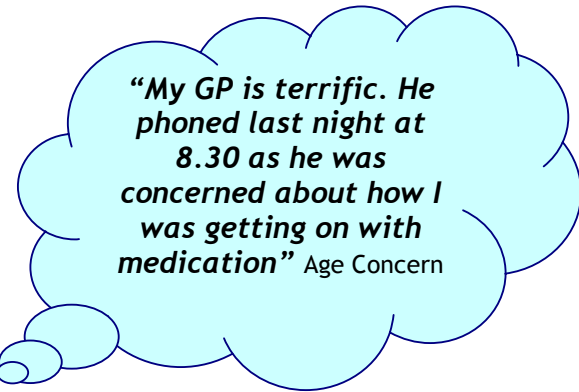
**1.10 Would the plans help improve people’s health or their access to healthcare?** There was qualified support for the idea that these plans could improve health and access to healthcare, subject to the various reservations on the individual proposals. However there were concerns that without more staff, changes in infrastructure would be of limited benefit whilst the funding and skills needed to deliver it all, were not guaranteed.



***“Yes - provided it is implemented in a sensible way.”***

Ramgarhia Sikh Association

**1.11 Quality of Healthcare - participants’ views:** the discussions prompted many comments about the quality of current health services which are described more fully in the report. While some participants had nothing but praise for their GP surgery and valued their personal relationship with him or her, many had negative experiences. The strongest themes on quality of primary care were difficulty in getting appointments, lack of



***“My GP is terrific. He phoned last night at 8.30 as he was concerned about how I was getting on with medication”*** Age Concern

accountability and discriminatory or insensitive attitudes. Poor administration, car parking, infections and lack of cleanliness were concerns expressed about the quality of hospital care.

**1.12 Equalities and Exclusions:** a number of themes emerged about equalities and excluding factors across the NHS generally. These included failure to understand and meet the needs of disabled adults and children, including people with mental health problems. Choice of the gender of doctors was an important priority for personal or cultural reasons, but was not always available. There were complaints of disadvantage for some ethnic groups because of lack of interpreting and translation services, especially in GP surgeries. Some participants complained of stigma on the grounds of their sexual orientation. Among excluding factors which participants complained of were ageism by health service professionals and a failure to understand and meet the needs of carers and those with long term conditions for accessible care. People with basic skills needs reported that they needed extra support to help them cope with medication and written information.

**1.13 Conclusion:** the process of conducting outreach consultation with the target groups was successful in engaging them and they are keen to be involved in the future. In some cases, their personal circumstances give them a range of needs which they are best equipped to describe and plan for. As a starting point, we have developed a Framework of Needs (see Chapter 7) to act as a metric against which to measure any further proposals or local plans. This Framework includes needs arising from discussion on the consultation proposals as well as issues raised by the groups which are not currently reflected in the plans. We recommend further patient and public involvement with similar groups so that the plans are developed in the way that best meets patients' needs and instils public confidence.

*"I was worried what would happen to my mum if I did not get back on time. Know what the Dr. said to me? 'You should look after these things before you come'". Carers UK*





---

i Index of Multiple Deprivation 2007 Department of Communities and Local Government