CONSULTATION WITH TRADITIONALLY UNDER REPRESENTED GROUPS ON THE SHAPE OF THINGS TO COME

19th JUNE 2009
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1. EXECUTIVE SUMMARY

1.1 Process
Health Link provided resources to support consultation by London Primary Care Trusts (PCTs) and Article 13 (commissioned by Healthcare for London) with traditionally under represented groups of particular relevance to stroke and major trauma, as identified in their Baseline Report. This exercise was part of the pan-London consultation *The shape of things to come*. Standard reporting material permitted PCTs to report findings of meetings, in the same format to allow some assessment of the process and easier analysis of the views expressed. This Executive Summary sets out the findings based on the data from those reports produced by the PCTs.

1.2 Groups consulted
46 groups were consulted, covering 1294 people and the most of the identified priority groups:
- There was consultation with housebound people who completed surveys but no other data was provided on their views;
- Although there was some consultation with people with heart condition, no data could be provided;
- 2 groups of mental health service users engaging with community services were consulted but no mental health inpatients;
- Ex offenders were consulted instead of prisoners;
- Carers were consulted, but not child carers.

1.3. Key questions in *The shape of things to come* and summary of responses:

1.3.1 Trauma Networks
- Proposals for trauma networks: 4
  - 32 groups expressed general support
  - 4 groups had doubts about the whole proposal
- Proposal for 4 trauma networks:
  - 29 groups supported 4 networks
  - 1 group preferred 3 networks
- Proposed options:
  - 19 groups supported Option 1 (including 4 content with Option 2);
  - 7 groups positively preferred Option 2 (2 by a majority);
  - 1 group preferred Option 3.

1.3.2 Stroke Care
- Proposals for stroke care overall:
  - 26 groups expressed general support:
  - 16 groups expressed doubts or concerns (including 4 who supported the proposals overall).
- Detailed proposals:
- 28 groups supported the proposal for 8 Hyper Acute Stroke Units; 10 groups expressed reservations (including 6 who supported);
- 19 groups supported the proposed locations of Hyper Acute Stroke Units; 12 expressed reservations (including 6 who supported);
- 20 groups supported the proposed locations for Stroke Units; 7 expressed reservations (including 5 who supported);
- 20 groups supported the proposed locations for TIA Services; 6 expressed reservations (including 4 who supported).

1.3.3 Criteria for PCT decision-making on the options
24 groups expressed support for all or some of the criteria. 3 groups made other suggestions or comments.

1.3.4 ‘No comment’ Responses
Many reports recorded ‘no comment’ on various topics or left answer boxes blank, which may affect interpretation of the above figures. The number of groups where no comments were recorded on a topic ranged from 8 groups for overall proposal for stroke care, through 10 on the overall proposal for trauma networks to 24 on proposed locations for TIA services.

1.4 Some Reservations and Concerns
Groups often expressed doubts, reservations and concerns, even when they supported a proposal. Many of these concerns were similar to those reported in Health Link’s original Consultation with ‘Traditionally Under Represented’ Groups on the Healthcare for London Proposals (2008) undertaken as part of pan-London consultations, Consulting the Capital.

- **Loss of Services:** The fear that the new services will result in hospital closures and a reduction in access to hospital services persists.
  
  “Some people remained unconvinced that a longer ambulance journey to a specialist centre would increase patients’ chances of survival.”
  
  Low income - Camden

- **Families, Friends and Carers:** The new pattern of services may mean that some patients will be in hospitals further away from their homes than is the case at present. Concern about how families, friends and carers will cope with this has persisted through both consultations. Low incomes, disability and older age could make visiting difficult for some people. Groups have wondered what facilities there will be for visitors and carers in the new centres. *The shape of things to come* did not discuss these issues. A facilitator of one group commented that hospitals would have to include plans for more accommodation for relatives on site, and that one hospital was training specialist nurse coordinators to help support relatives. So it seems that some thought may be being given to the needs of relatives at least at some centres.
- **Travel Times:** A persistent anxiety is about ambulance travel times, their impact on the recovery of patients and whether they can consistently be within the targets. *The shape of things to come* addressed both these concerns with evidence that both these concerns are being met (the benefits of improved treatment outweigh the increase in travel time anticipated, and the ambulance services own records indicate that the target times will be achieved). A number of groups remained sceptical, particularly about meeting the target times.

- **Carers:** Views of carers were covered in the earlier Health Link consultation with traditionally under represented groups on *Consulting the Capital* and in Healthcare for London’s own pre-consultation engagement with major trauma and stroke patients and carers in preparation for *The shape of things to come*. The PCTs consulted groups of carers in the present exercise. Reports from PCTs indicated that carers consulted commented more on the proposals themselves than on their own role in relation to services.

- **Paramedic Skills:** A number of groups commented on the crucial role that paramedics will play in the new arrangements. In the earlier consultation some groups expressed scepticism about their skills. *The shape of things to come* notes the importance of relevant skills for paramedics and the ambulance service more widely, and indicates that further training is being put in place.

- **Communication:** A number of groups have referred to the continuing importance of clear communication in plain English, with interpreting and translation as necessary.

- **Long Term Illness or Disability:** Groups recognised that patients being treated in the new centres for major trauma or stroke will sometimes have a long term illness of disability and were concerned that staff in the centres need to be aware of long-term conditions of individual patients and take account of these in their treatment.

- **Groups Vulnerable to Prejudice or Stigma:** Discrimination and prejudice may also occur in relation to culture, religion, race, gender, sexual orientation, gender reassignment, age etc. For example, for some religious groups there are specific requirements in relation to end of life. Groups with learning difficulties, mental health problems etc. felt that they are sometimes subjected to discrimination and prejudice within the NHS.

- **Capacity:** Some groups raised concerns about the capacity of the new services to meet the demands, with one noting that major trauma centres could themselves become targets for terrorists in a concerted attack.

1.5. **View on process**

Some groups expressed appreciation at being consulted and others stressed the importance of continuing to be involved.

> “If you’ve had a stroke, how will the ambulance staff know which of the units to take you to?”

Refugees, Travellers, BME & Others - Sutton & Merton
With respect to the criteria, one group suggested including customer service and patient satisfaction as a criterion.

1.6 Conclusions
The consultation has found overall support for all the proposals for major trauma and stroke care contained in *The shape of things to come*, with various reservations and concerns (see 1.4 above) which may usefully be taken into consideration in the implementation of the proposals.

2. INTRODUCTION

2.1 Background
During 2007, Professor Lord Darzi developed a strategy on behalf of NHS London to meet Londoners' health needs over the next ten years, *A Framework for Action*.


Health Link’s report, *Consultation with ‘Traditionally Under Represented’ Groups on the Healthcare for London Proposals* was published in March 2008. This was based on views gathered in 36 meetings with traditionally under represented groups across London.

Also in March 2008, the London Health Commission published *Health Inequalities and Equality Impact Assessment of ‘Healthcare for London: consulting the capital’*. Among other themes this report explores stroke pathways, but it does not address major trauma.

2.2 Pan London Work On Major Trauma And Stroke Services
Prior to the launch of detailed proposals on major trauma and stroke services (*The shape of things to come*, see below) Healthcare for London consulted:

(a) for stroke, a clinical expert panel which involved health professionals from all parts of the stroke pathway; a patient panel, and representative organisations including Connect, Crossroads Association, Princess Royal Trust for Carers, Different Strokes and The Stroke Association; and

(b) for major trauma, a clinical expert panel which involved health professionals from every speciality involved in trauma care; a patient panel; and representative organisations including Headway and the Spinal Injuries Association.

Both projects held stakeholder events during the development of the proposals. Other pre-consultation engagement included events for nurses, allied health professionals and maternity staff.

“Most attendees agreed that having a specialised centre was a good idea. You will have the right people in the right place.”
Stroke - Sutton and Merton
2.3 The shape of things to come
On 30 January 2009 primary care trusts in London and South West Essex, supported by Healthcare for London, launched a consultation on stroke and major trauma services in the capital. A consultation document, *The shape of things to come*, was published outlining specific proposals on new, high-quality major trauma and stroke services for London. A compact version of the consultation document was published in a variety of formats including audio, Braille, easy read, easy access and large print, and translated into 15 languages. The consultation document included a questionnaire for readers to complete and return to the independent assessors of the consultation, Ipsos Mori. To support the consultation and ensure that responses from people in traditionally under represented groups were obtained, Healthcare for London commissioned Health Link to undertake a four stage project:

- **Stage One** - Views so far: To identify and review the views of traditionally under represented groups on *Consulting the Capital* which were relevant to stroke and trauma care;
- **Stage Two** - Evidence for selection of groups: To identify traditionally under represented population groups likely to have specific views on the incidence of and treatment for stroke and trauma care;
- **Stage Three** - Resources: Building on the output of Stages One and Two to develop recommendations and resources for PCTs on the methodology appropriate to consultation with the identified groups;
- **Stage Four** - Report: To present the views of traditionally under-represented groups on stroke and trauma care, on the basis of the PCT submissions.

At the end of March 2009 Health Link produced a *Review of Views expressed by Patients, Carers, and Traditionally Under Represented Groups relating to the Major Trauma and Stroke Services Baseline Report*. This report and its recommendations comprise:

- **a)** Views relevant to stroke and major trauma expressed during our earlier pan-London consultation with traditionally under represented groups on the Healthcare for London proposals (*Consulting the Capital*), and the views of patients and carers obtained in Healthcare for London’s pre-consultation engagement;
- **b)** Relevant demographic information for London boroughs;
- **c)** Recommendations on which traditionally under represented groups to consult on stroke and major trauma, and why (listed below);
- **d)** Resources to support local consultation and consistent reporting.

London PCTs and Article 13 (an independent organisation) have now undertaken consultation with traditionally under represented groups in their areas. This report gives an account of that work and its findings, drawing out conclusions and recommendations.

| TABLE 1 - MINIMUM RECOMMENDED GROUPS FOR CONSULTATION ON MAJOR AND TRAUMA & STROKE |
|---------------------------------|---------------------------------|
| Asian or Asian British          | Older people                    |
| Black or Black British          | Other ethnic groups             |
| Buddhist                        | Heart condition                 |
| Care home residents             | Hypertension or TIA history     |
| Carers including child carers   | Living on low incomes           |
| Chinese                         | Learning disability             |
| Christian                       | Diabetes                        |

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### TABLE 1 - MINIMUM RECOMMENDED GROUPS FOR CONSULTATION ON MAJOR AND TRAUMA & STROKE

<table>
<thead>
<tr>
<th>Hindu</th>
<th>Physical or sensory disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housebound people</td>
<td>Limited basic skills</td>
</tr>
<tr>
<td>Jewish</td>
<td>Long term conditions</td>
</tr>
<tr>
<td>Lesbian, gay, bi-sexual, transgender</td>
<td>Prisoners</td>
</tr>
<tr>
<td>Mental health service users (IP)</td>
<td>Sikh</td>
</tr>
<tr>
<td>Mental health service users (OP)</td>
<td>Women</td>
</tr>
<tr>
<td>Mixed ethnicity</td>
<td>Young people</td>
</tr>
<tr>
<td>Muslim</td>
<td></td>
</tr>
</tbody>
</table>

### 3. METHODOLOGY OF LOCAL CONSULTATIONS WITH TRADITIONALLY UNDER REPRESENTED GROUPS

Healthcare for London asked the PCTs to consult one or more of the traditionally under represented groups on the list recommended by Health Link in the Baseline Report in their areas and commissioned Article 13 to consult certain specific groups. The PCTs and Article 13 used the Health Link report *Consultation with Traditionally Under Represented Groups on ‘The shape of things to come’: Resources* (March 2009) (the Resources pack) to guide their consultations and as a framework for reporting.

The resulting feedback reports were analysed by Health Link and this report was produced for Healthcare for London.

#### 3.1 Arranging the Local Consultations

Drawing on the Baseline Report and Health Link’s experience of consultation with traditionally under represented groups, Health Link produced the Resources pack to guide local consultations. In order to promote diverse, local consultation on the proposals in *The shape of things to come*, Healthcare for London:

- asked the PCTs to choose one or more traditionally under represented groups in their area, on the basis of guidance in the Resources pack;
- commissioned Article 13 to take on certain groups which the PCTs were unable to engage.

The PCTs and Article 13 carried out the consultations in April and early May 2009. They endeavoured to follow the procedure described in the Resources pack and they reported the feedback via pro forma templates provided in the Resources pack.

#### 3.2 Processing Local Consultation Reports

Working to a tight timetable of about seven weeks, the PCTs and Article 13 were to complete the consultations and return their reports to Healthcare for London as soon as possible and not later than early May 2009. When the reports were received by Healthcare for London they were passed on to Health Link for processing and analysis.

Health Link processed and analysed the reports as follows:

- We scanned the reports to ensure that they met minimum standards in terms of reporting responses and quality criteria. If any report did not meet these standards, we would discuss with the PCT or Article 13 and explore whether additional work could be undertaken to produce a satisfactory report.
We scanned the satisfactory reports to identify any gaps in information and contacted the relevant PCT or Article 13 to request the missing information if available.

We analysed the views expressed by the participants using qualitative software supplemented by a manual review.

When all the reports had been analysed we collated and summarised the findings, compared them with the findings reported in the Baseline Report, drew our conclusions and recommendations.

3.3 Background Information to Support Local PCT Consultations

3.3.1 Resources Pack
The Resources pack set the local consultation in the context of Consulting the Capital and The shape of things to come and provided guidance on consulting traditionally under represented groups based on experience that traditional engagement processes risk being abstract, jargon bound and irrelevant to service users - with views culled but seemingly ignored. The resource pack includes suggestions and materials to support engagement that:

- is effective from the participants’ point of view;
- generates ideas to contribute to reducing health inequalities;
- creates diverse ‘consultation capital’ for future engagement.

The Resources pack discussed a number of factors that support targeting of particular groups for consultation on stroke and major trauma care:

- incidence and risk (all groups known to be at higher risk of major trauma and stroke are within traditionally under represented categories);
- status as a carer;
- access;
- legal equality groups;
- groups at risk of exclusion from participation;
- demographic variations between boroughs (while the demography of traditionally under represented groups in London boroughs shows very pronounced variation only in relation to ethnicity and deprivation, there is a strong case for ensuring that a population group which is markedly under represented in a borough is included in consultation).

The pack also:

- drew attention to the legal requirements for consultation in relation to timeliness, content, length and outcome;
- discouraged the use of PowerPoint presentations, recommending instead the use of posters and handouts, which participants could study at their own pace;
- recommended starting with the users’ perspective and avoiding jargon.

3.3.2 Guidance on accessing Traditionally Under Represented Groups
The Resources pack provided background on how the target groups (see above) were identified for this consultation. Each PCT was asked to take account of the fact that it might have very well developed links with, for example, disability or BME groups, so that these groups generally responded well to consultations and were not under represented in that PCT’s locality.

The Resources pack suggested various agencies to assist PCTs and Article 13 to locate appropriate organisations which supported under represented groups in their localities. The pack recommended contacting organisations by various means including email and
letter, taking account of the variability in the resources of the organisations, and following up as necessary initial attempts at making contact. The pack suggested a range of involvement methods, although the preferred method was to conduct the consultation session at an existing meeting of the group at its own premises (already shown to be a good way of overcoming barriers to engagement). Goodwill payments could be offered to host organisations and participants when appropriate.

3.3.3 The Ethics of Involvement with Traditionally Under Represented Groups
The Resources pack recommended PCTs and Article 13 to take account of 6 ethical principles:
- Consultation and involvement is not ‘something for nothing’;
- Participants’ views on topics not being consulted upon are equally valid;
- People should feel they have more power as a result of the consultation;
- The consultation should meet the needs of participants as well as the needs of those doing the consulting;
- Different groups have different needs which should shape the consultation;
- Participants should not be left out of pocket or put at risk of being financially worse off as a result of their engagement.

3.3.4 Criteria for Successful Consultation with Traditionally Under Represented Groups
The Resources pack specified six criteria for the conduct of consultation meetings with traditionally under represented groups, to enable quality control of the consultations:

Criterion 1 - Diverse Engagement
Criterion 2 - Focus and Clarity
Criterion 3 - Effectiveness
Criterion 4 - Openness
Criterion 5 - Ethical consultation
Criterion 6 - Accessibility.

The pack made suggestions as to how consultation meetings could be conducted to meet the criteria.

3.3.5 Pro Forma for Reporting Consultation
The pack included a template for recording views, to facilitate consistency and fairness, and to monitor quality of the process against criteria. It recommended feeding back to the group the record of what they had said so that additions and corrections could be made.

The sections of the pro forma were:
1. PCT details
2. Group meeting details
3. Methodology
4. Findings
   a. Views on The shape of things to come
   b. Other issues raised
5. Criteria for an effective inclusive consultation with traditionally under represented groups

The pack also included an Evaluation Form which participants could fill in anonymously to test whether enough information had been given in a sufficiently accessible form to permit intelligent consideration.
Finally, the pack included a demographic form for participants to complete, but it acknowledged that not all participants would want to fill this in.

### 3.4 The Consultations in Practice

25 London PCTs (out of a possible 31 PCTs) and Article 13 (an independent organisation commissioned directly by Healthcare for London) carried out consultations with traditionally under represented groups. They produced 46 reports, as a number of them consulted more than one group.

The aim was to consult people within all the traditionally under represented groups identified as appropriate in the *Resources* pack. As can be seen from the Table overleaf the PCTs and Article 13 succeeded in covering most categories, with a few exceptions:

- There was consultation with housebound people who completed surveys but no other data was provided on their views;
- Although there was some consultation with people with heart conditions, no data could be provided;
- 2 groups of mental health service users engaging with community services were consulted but no mental health inpatients;
- Ex offenders were consulted instead of prisoners;
- Carers were consulted, but not child carers.

Between them Article 13 and the PCTs consulted a total of 1,294 people. This included two atypical consultations, each with about 300 people, with members of the Hindu community and members of the Sikh community. Other groups consulted ranged in size from 4 people to 60 people, with an average of 28 people.

Article 13 and many of the PCTs followed the guidance in the *Resources* pack fairly closely and made their returns using the templates and guidance provided. Some, however, filled in the Findings (Section 4) and Criteria (Section 5, important for quality control) in ways which provided less information than we would have hoped. 9 of the reports were accompanied by a set of Evaluation Forms and 7 of the reports were accompanied by Demographic Forms. Some PCTs contracted out the consultation to organisations who they thought were more able to engage a relevant group - Islington used the Elfrida Society and Redbridge used the Daffodil Advocacy Project, both for people with learning difficulties/disability.

Four PCTs did not use the *Resources* pack and ten made returns on other forms. We adapted the information which they had provided as best we could to fill in the relevant sections of the Health Link forms, to enable us to process the material, but there were numerous ‘no recorded views’ on various questions as a consequence.

The Table overleaf shows how many participants there were at each meeting and which PCT consulted which group.
<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>ORGANISATION</th>
<th>CONDUCTED BY</th>
<th>ATTENDEES</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Asian (female)</td>
<td>Sree Narayana Guru Mission</td>
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<td>2. Black British (Long Term Condition)</td>
<td>Sickle Cell User Grp.</td>
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<td>3. Black British (Older)</td>
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<td>5. BME 2</td>
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<td>6. Buddhists</td>
<td>True Buddha Temple (Willesden)</td>
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<td>7. Care home residents</td>
<td>Jewish Care</td>
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<td>Carers Partnership Grp.</td>
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<td>9. Carers 2 (support workers)</td>
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<td>12. Christians</td>
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<td>26. Limited Basic skills</td>
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<td>27. Long term Condition 1</td>
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<td>31. Mental Health</td>
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<td>CATEGORY</td>
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<td>CONDUCTED BY</td>
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<td>35. Older people 3</td>
<td>OPeN</td>
<td>NHS Croydon</td>
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<td>36. Older people 4</td>
<td>Partnership for Older People</td>
<td>NHS Croydon</td>
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<td>38. Other Ethnic</td>
<td>Turkish &amp; Cypriot Women’s Project</td>
<td>NHS Haringey</td>
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<td>41. Stroke 1</td>
<td>Ealing Stroke Club</td>
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<td>42. Stroke 2</td>
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<td>43. Stroke 3</td>
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<td>44. Women (mental health)</td>
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<td>45. Young people 1</td>
<td>Brits school Croydon</td>
<td>Article 13</td>
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<tr>
<td>46. Young people 2 (male)</td>
<td>Rutlish School</td>
<td>Wandsworth Teaching PCT</td>
<td>6</td>
</tr>
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</table>
4. FINDINGS

All findings are summarised in Table 3 at this end of this section.

4.1 Major Trauma

4.1.1 Proposal for Trauma Networks

32 groups expressed general support for the proposal on trauma networks.

General Support for the Proposals for Trauma Networks

- All fine. Sickle Cell user group - Black or Black British
- Takes you straight away to the right place (where they can treat you properly). True Buddha temple - Buddhists
- Attendees understood and agreed with the rationale for four major trauma units. Southwark for Jesus - Christians
- I think it is a good idea. Latch House - Ex offenders
- In agreement with specialist hospitals. Hillingdon stroke aftercare
- Happy with options. Partnership for older people - older people

No comments were recorded for 10 groups.

Various reservations were expressed by 14 groups, 4 of whom had doubts about the whole proposal while 10 expressed general support subject to reservations.

- What would happen if there were a major national emergency, such as that Heathrow plane accident, where would the injured be treated? Every centre should be equipped as a major trauma centre in case of emergency.
- Some concerns were expressed about the impact on a hospital of being a major trauma centre and on the existing accident and emergency services.
- The group would like to read the document and then think about the options.
- Some concerns regarding timing.
- We are worried that 45 minutes is too long to get to a major trauma centre. Is there any way this time can be cut down? We think people may die.
- 4 trauma centres may get full very quickly.
- Will all the trauma centres have helicopter access?
- Where will trauma cases on M25 go? What will happen with Surrey patients?
- Depends on what happens i.e. major emergency.
- Traffic at Tooting is bad.
- Carers’ and relatives’ potential difficulties in supporting the injured away from home and problems with rehabilitation.
- It’s a concern that traffic would impede ambulances and patients’ chances of survival will be diminished.
- Concern about access for family visits if specialist centres are further away.
- A little concern about travel time.
- Can the trauma centres really be reached within the stated time?
- What would happen if there was a terrorist attack in London?
Why do we need specialist units, what’s wrong with the hospital care we get now?

4.1.2 How Many Networks?
29 groups expressed a preference for 4 networks, usually because they preferred more rather than fewer major trauma centres.

1 group expressed a preference for 3 networks, citing cost and staffing issues.

1 group expressed doubts.

No preferences were recorded for 15 groups.

4.1.3 Preferred Network
19 groups would prefer or be content with Option 1: The Royal London Hospital, King’s College Hospital, St George’s Hospital and St Mary’s Hospital; 4 of these groups would be equally content with the second option.

11 groups would prefer or be content with Option 2: The Royal London Hospital, King’s College Hospital, St George’s Hospital and The Royal Free Hospital; 4 of these groups would be equally content with the first option.

One group would prefer Option 3: The Royal London Hospital, King’s College Hospital and St George’s Hospital.

No preferences were recorded for 19 groups.

Reasons for preferring Option 1 or Option 2 were usually about how well the hospitals were spread around London, transport links, the nearness of a hospital to a particular group, and familiarity with or approval or disapproval of a particular hospital.

4.1.4 Other options
Some people in one group asked why Charing Cross wasn’t a potential Major Trauma Centre.

One group asked why Homerton Hospital had not been mentioned in the consultation on trauma.

4.1.5 Other Issues Relevant only to Major Trauma
A number of other issues were raised which were relevant to both stroke and major trauma. These are summarised in paragraph 6.3. Other issues raised relevant only to major trauma, raised in each case by only one group, were:

- There could be discrimination regarding gun shot wounds, being in a gang, and having a criminal record;

“We need Drs and clinics with a specific expertise, not generic skills, in order to provide the best care”
Learning Disability - Action on Disability Kensington & Chelsea
- The risk of a major terrorist attack should be taken into account in planning for major trauma (see also reservations about the overall proposals in relation to terrorism and major accidents);
- Possibility that major trauma centres themselves could become possible targets for terrorists.

4.2 Stroke Care

4.2.1 Overall Proposal for Stroke Care
26 of the 46 groups expressed general support for the proposals for stroke care.

**General Support for the Proposals for Stroke Care**

- Participants quickly recognised the proposed concept and agreed with the considerations. True Buddha Temple- Buddhists
- Treating stroke as an emergency was very important as well as all strokes being taken to the closest HASU. Carers Partnership Group- Carers
- The group felt clinicians were best placed to produce stroke care plans. Chinese Community Centre- Chinese
- Attendees were positive about the proposals overall. Southwark for Jesus- Christians
- They concurred with the proposals, and recognise that it made sense to concentrate activity in those hospitals that were able because of capacity, expertise and location - to respond quickly in the event of stroke. Health Community Team- Jewish
- It seems like such an obvious thing to do so why do we have to wait for HASUs to happen? Limbless Association & Roehampton Limb user group- Disability
- Having a specialist centre is a good idea as you will have the right people in the right place. Stroke Association Dysphasia Stroke Group- Stroke patients

16 groups expressed doubts or concerns, including 4 who supported the proposals overall.

**Reservations**
- Concern that there is currently a lack of preventative information and services, especially for those with diabetes, and we were not confident that the proposals will necessarily address this.
- There needs to be a specialist in Sickle Cell care at the eight HASUs.
- Is the 30 minutes time to get stroke patients to St George’s achievable for the whole of Croydon?
- There were concerns about travel time to proposed hyper-acute and other units and some members found the data about blue light travel time implausible.
- Existing services would be removed locally which would be a big loss, even if new services will be set up at a further distance.

© Health Link May 2009
We think people should be treated within 1 hour of having a stroke to make sure they are less disabled. We think 3 hours is too long.

If a patient has a stroke at (say) Ealing Hospital, what will happen to them? Will they have to be taken to a HASU mid-operation?

Some general concerns about whether the plans are affordable.

How will ambulance drivers decide whether to take people to a hyper-acute stroke unit or just to the nearest hospital with a stroke unit?

Some cynicism about whether planned changes will come to fruition and really improve services.

Will planned services have sufficient capacity?

Concern about access for family visits if specialist centres are further away.

Can the Hyper Acute Stroke Units really be reached within the stated time?

Why do we need specialist units, what’s wrong with the hospital care we get now?

No views were recorded for 8 groups.

4.2.2 Proposal for 8 Hyper Acute Stroke Units

28 groups expressed support for this proposal.

10 groups expressed doubts or reservations, including 6 groups which supported the proposal.

**Reservations**

The group members wanted reassurance that every HASU would have specialist sickle-cell knowledge and equipment. They talked about their past experience with sickle-cell related strokes, and about how they had felt sidelined.

Wanted services to be locally based at either Barnet Hospital or The Royal Free Hospital.

What happens if a patient goes to Mayday Hospital with a suspected stroke, will they be sent away?

How efficiently will the plans be put into place? Where will all the staff come from?

There was concern that one or more of the HASUs may find that it lacks the capacity for the expected level of demand.

Some people argued that there should be more units.

Concerns that it will be more difficult for relatives and carers to visit patients when they are not in their local hospital.

What standards would the acute stroke units need to meet?

No views were recorded for 14 groups.

4.2.3 Proposed Locations for 8 HASUs

19 groups expressed support for the proposed locations.
12 groups expressed doubts about the locations, including 6 groups which supported the proposed locations.

**Reservations**

- Participants questioned the concentration of units in the centre of the city.
- There was concern about the loss of Ealing Hospital Stroke Unit.
- Those who were sceptical of the 30 minute journey time were also unsure that the current proposals would provide the necessary level of coverage.
- HASUs are not evenly spread enough - especially in North London and the South West.

1 group rejected the proposed sites: Participants did not want any of the preferred locations. 1 group was split and no views were recorded for 19 groups.

**Alternative Sites & Suggested Identification Criteria**

- St Mary’s Hospital was suggested as some members thought it a good hospital.
- Why are they all in the middle and not round the edge?
- The group wasn’t sure about the whole of London but felt that UCL and St Mary’s should be amongst them.
- HASUs should be spread out evenly across London.
- Barnet Hospital
- Royal Free Hospital
- Mile End Hospital
- Hillingdon Hospital
- Newham Hospital
- Ealing Hospital
- One per borough
- One attendee wanted care to be local.
4.2.4 Proposed Locations for 21 Stroke Units
20 groups expressed support for the proposed locations, often because a local hospital was included.

<table>
<thead>
<tr>
<th>Support for Proposed Locations of 21 Stroke Units</th>
</tr>
</thead>
<tbody>
<tr>
<td>✔ Agreed would meet the needs of the population.</td>
</tr>
<tr>
<td>✔ Most people had no idea where the majority of these hospitals were. We focused on the ones in west London and most seemed happy with the selection.</td>
</tr>
</tbody>
</table>
| ✔ Supported locations: includes local hospitals. Jewish care-
  Care home residents |
| ✔ It was positive that Lewisham Hospital would still provide specialist care. Carers Lewisham- Carers of Stroke Survivors |
| ✔ Generally pleased that Mayday Hospital is a stroke unit. Carers partnership group- Carers |
| ✔ Importance of being close to home so that family and friends can support recovery. Navnat Darpan Vanik Association of the UK- Hindu |

7 groups expressed doubts including 5 which supported the locations generally. Most of the doubts were concerned with spread and local access. Ealing and Whittington Hospitals were suggested as alternative or additional locations. 1 group rejected the proposed locations and 1 was split.

No views were recorded for 22 groups.

4.2.5 Proposed Locations for 21 TIAs
20 groups expressed support for the proposed locations, often because a local hospital was included, including one group that had some doubts.

6 groups expressed doubts, (including 4 who supported) mainly concerned with spread and local access, including one group which supported the locations overall. Ealing, Homerton, Newham and Whittington Hospitals were suggested as alternatives. 1 group suggested that there should be 1 TIA service per borough.

No views were recorded for 24 groups.

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4.2.6 Other issues relevant only to stroke
None

4.3. Other issues raised, relevant to both stroke and major trauma
5 groups commented on the roles of the paramedics and ambulances. They expressed concern about travel time for ambulances. They wondered whether paramedics had sufficient training about making the right diagnosis to ensure that the patient was taken to the appropriate unit, and about conditions other than the main focus of the crisis, e.g. mental health.

2 groups raised the issue of the need for appropriate interpreting and translating - we get asked a lot of questions that are not in our language.

Two groups expressed concern about the clinicians having adequate information about the patient’s health history - my notes took a long time to catch me up. One of the two groups was also concerned about privacy.

Isolated comments from individual groups are summarised below:
- Concern about appropriate procedures (according to their religion) at end of life and after death. Links with relevant religious organisations were necessary to ensure that guidance was available;
- Importance of adequate facilities for families and friends (see also reservations about the overall proposals in relation to families and carers);
- Anxiety over consent forms - we need more communication and explanation when we are being asked to sign a consent form - not just as I am about to have a major procedure;
- Concern about NHS staff expressing prejudice through silly snide comments;
- Concern that the consultation document was not reader friendly;
- Concern about the cost of the new services. A number of participants wanted reassurances that increased investment in major trauma and stroke would not mean other areas of the health service would suffer as a result. Some people were also concerned that taxes would have to rise in order to pay for the proposals. However, many participants also believed that higher expenditure now would benefit Londoner’s health in the future, and that the proposals represent good value for money;
- Concern about the recruitment, training and cost of staff;
- Recognition that the proposals will require a high level of co-operation between various organisations within and beyond the NHS. This was seen as potentially beneficial, but there was concern that the various stakeholders will not be able to work effectively with one another;
- Concern about political decisions: I am worried about the politics; people are territorial and have loyalties to ‘their’ hospital;
It’s good that people want to know what we think.

4.4. Criteria for Decision Making

9 groups supported all three recommended criteria. In addition to these 9 groups:

- 6 groups considered the criterion of best clinical quality to be particularly important (paramount according to one group).
- 8 groups considered the criterion of best geographical coverage to be particularly important, because of ambulance travel time as one group stated. 3 of these also considered best clinical quality to be an essential criterion.
- 1 group considered Best fit between the two services or with other services to be the most important criterion.

In relation to Best clinical quality 1 group wanted to know whether patients’ notes and understanding of Long Term Conditions would be available to the receiving hospital. They commented that for diabetics it was important that the clinical team work with the family to ensure normal medication and insulin regime were resumed as soon as possible. We would want to know that expertise in diabetes care was available within the stroke team.

One group suggested that a number of factors needed to be considered:

- Staff training to understand the difference between TIA (transient ischaemic attack) and CVA (cerebrovascular accident).
- Issues regarding workforce and reception staff numbers (mentioned by at least one other group).
- Upskilling and training of local ambulance service.
- Need to consider a carer’s ability to get to the hospital.
- Parking.
- Accessibility by public transport for visitors.
- Reception area and knowledge of receptionists is important.
- Travel times need to be kept under review.
- We must have a say in how services are implemented.
- Too much time wasted answering questions when calling 999.

Another group raised a variety of issues:

- They need to look at maximising the greater good by providing fair and equal services for all people living in the city, and not be influenced by localism.
- Participants thought ‘best fit with other services and strategic objectives’ as vague. It looked like a ‘get out clause’.
- The criteria should include the monetary implications of the different proposals - important to judge proposals against the relative value for money they will create.
- The views of staff (in particular front line staff like paramedics) should be contemplated in the decision making process.

Other comments:
Customer service and patient satisfaction should be considered.

But why not experts everywhere?

Should be based on travel time and best equipped hospitals.

4.5. Levels of Support for Proposals

46 groups were consulted, with the following results for the key questions in The shape of things to come, illustrated in Table 3 overleaf:

- **Proposals for trauma networks**
  - 32 groups expressed general support
  - 14 groups expressed doubts or reservations (including 10 who supported the proposal overall)
  - 10 groups had no views recorded

- **Proposal for 4 trauma networks**
  - 29 groups supported 4 networks
  - 1 group preferred 3 networks
  - 1 expressed doubts
  - 15 groups had no views recorded

- **Proposed options**
  - 19 groups supported Option 1 (including 4 content with Option 2)
  - 7 groups positively preferred Option 2 (including 2 by a majority)
  - 1 group preferred Option 3
  - 19 groups had no views recorded

- **Proposals for stroke care overall**
  - 26 groups expressed general support
  - 16 groups expressed doubts or concerns (including 4 who supported the proposals overall)
  - 8 groups had no views recorded

- **Proposal for 8 HASUs**
  - 28 groups supported the proposal
  - 10 groups expressed reservations (including 6 who supported)
  - 14 groups had no views recorded

- **Proposed locations of HASUs**
  - 19 groups supported the proposed locations
  - 12 expressed reservations (including 6 who supported)
  - 1 group rejected all locations
  - 1 group was split
  - 19 groups had no views recorded

- **Proposed locations for 21 stroke units**
  - 20 groups supported the proposed locations
  - 7 expressed reservations (including 5 who supported)
  - 1 group rejected all locations and 1 was split
  - 22 groups had no views recorded

- **Proposed locations for 21 TIA units**
  - 20 groups supported the proposed locations
  - 6 expressed reservations (including 4 who supported)
  - 24 groups had no views recorded

- **Criteria for decision making**
  - 24 groups supported all or some of the criteria
  - 3 groups made other suggestions or comments
  - 19 groups had no views recorded.
<table>
<thead>
<tr>
<th>GROUP (Additional Category)</th>
<th>MAJOR TRAUMA</th>
<th>STROKE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Asian women</td>
<td>Y+?</td>
<td>4</td>
</tr>
<tr>
<td>2. Black British (Long Term Condition)</td>
<td>Y+?</td>
<td>4</td>
</tr>
<tr>
<td>3. Black British (Older)</td>
<td>Y</td>
<td>4</td>
</tr>
<tr>
<td>4. BME 1 (Mixed)</td>
<td>Y</td>
<td>4</td>
</tr>
<tr>
<td>5. BME 2</td>
<td>Y</td>
<td>4</td>
</tr>
<tr>
<td>6. Buddhists</td>
<td>Y</td>
<td>4</td>
</tr>
<tr>
<td>7. Care home residents</td>
<td>Y</td>
<td>4</td>
</tr>
<tr>
<td>8. Carers 1</td>
<td>Y+?</td>
<td>4</td>
</tr>
<tr>
<td>10. Carers 3 (stroke survivors)</td>
<td>Y</td>
<td>4</td>
</tr>
<tr>
<td>11. Chinese</td>
<td>Y</td>
<td>4</td>
</tr>
<tr>
<td>12. Christians</td>
<td>Y</td>
<td>4</td>
</tr>
<tr>
<td>13. Diabetes 1</td>
<td>Y+?</td>
<td>4</td>
</tr>
<tr>
<td>14. Diabetes 2</td>
<td>Y</td>
<td>4</td>
</tr>
<tr>
<td>15. Disability 1</td>
<td>Y+?</td>
<td>4</td>
</tr>
<tr>
<td>16. Disability 2</td>
<td>Y</td>
<td>4</td>
</tr>
<tr>
<td>17. Ex offenders</td>
<td>Y</td>
<td>4</td>
</tr>
<tr>
<td>18. Hindu</td>
<td>Y</td>
<td>4</td>
</tr>
<tr>
<td>19. Jewish</td>
<td>Y</td>
<td>4</td>
</tr>
<tr>
<td>20. Learning Disability 1</td>
<td>Y+?</td>
<td>4</td>
</tr>
<tr>
<td>21. Learning Disability 2</td>
<td>Y+?</td>
<td>4</td>
</tr>
<tr>
<td>22. Learning Disability 3</td>
<td>Y+?</td>
<td>4</td>
</tr>
<tr>
<td>23. Learning Disability 4</td>
<td>Y+?</td>
<td>4</td>
</tr>
<tr>
<td>24. Learning Disability 5</td>
<td>Y+?</td>
<td>4</td>
</tr>
<tr>
<td>GROUP (Additional Category)</td>
<td>MAJOR TRAUMA</td>
<td>STROKE</td>
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<tr>
<td></td>
<td>Trauma</td>
<td>Stroke</td>
</tr>
<tr>
<td></td>
<td>networks?</td>
<td>care?</td>
</tr>
<tr>
<td></td>
<td>Network</td>
<td>8 HASUs</td>
</tr>
<tr>
<td></td>
<td>Options?</td>
<td>Locations?</td>
</tr>
</tbody>
</table>

### MAJOR TRAUMA

| 25. LGBT | ? | Y | Y+? |
| 26. Limited Basic skills | ? | Y | Y+? |
| 27. Long Term Condition 1 | Y | Y+? |
| 28. Long Term Condition 2 | Y | Y+? |
| 29. Low Incomes 1 | Y+? | (2, 3) | Y+? |
| 30. Low Incomes 2 | Y+? | 4 | Y+? |
| 31. Mental Health | ? | Y+? |
| 32. Muslims | 4 | N |
| 33. Older People 1 | ? | Y+? |
| 34. Older People 2 | ? | Y+? |
| 35. Older People 3 | Y | Y+? |
| 36. Older People 4 | Y | ? |
| 37. Older People 5 (BME) | Y+? | Y+? |
| 38. Other Ethnic | Y | Y+? |
| 39. Refugees, (Travellers, BME + other) | Y+? | Y+? |
| 40. Sikh | Y | Y+? |
| 41. Stroke 1 | Y | Y+? |
| 42. Stroke 2 | Y | Y |
| 43. Strokes 3 | Y | Y |
| 44. Women (mental health) | Y | Y+? |
| 45. Young people 1 | Y+? | Y+? |
| 46. Young people 2 (male) | Y | Y+? |

### STROKE

| 43. Strokes 3 | ? |
| 44. Women (mental health) | ? |
| 45. Young people 1 | ? |
| 46. Young people 2 (male) | ? |

### KEY

| NO COMMENT RECORDED/UNCLEAR | Y: SUPPORTIVE | Y+?: YES+RESERVATIONS | ?: DOUBTS | N: NO | DK: DON’T KNOW |
4.6 Doubts, Reservations and Concerns

4.6.1 Issues common to *Consulting the Capital* and *The shape of things to come*

There was a degree of commonality between the findings of *Consulting Capital* and *The shape of things to come*, as indicated in the Table below.

<table>
<thead>
<tr>
<th></th>
<th>Views of traditionally under represented groups from <em>Consulting the Capital</em></th>
<th>Views of traditionally under represented groups from <em>The shape of things to come</em></th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk of reduction in access to services.</td>
<td>Concern about impact of new services on local services or on services in the hospitals where specialist centres are located. Preference for local service by some people.</td>
<td></td>
</tr>
<tr>
<td>Risk of hospital or service closures.</td>
<td>Concern about impact of new services on local services. Preference for local service by some people.</td>
<td></td>
</tr>
<tr>
<td>Concern about ambulance travel times.</td>
<td>Scepticism about the ability of ambulances always to reach the hospital within the target-time.</td>
<td></td>
</tr>
<tr>
<td>Concern about consequences of longer ambulance travel times for recovery of patient.</td>
<td>Concern that increased travel time (even within the target) may not be in the patient’s interest and could hamper their recovery.</td>
<td></td>
</tr>
<tr>
<td>Concern about travel and access for family, friends and carers.</td>
<td>Concern about the consequences for family, friends and carers confronted with long travel times to visit; questions about facilities for families, friends and carers at the specialist hospitals.</td>
<td></td>
</tr>
<tr>
<td>Scepticism about skills of paramedics.</td>
<td>Crucial role of paramedics in preliminary diagnosis and decision as to where to take a patient. Importance of staff training at all levels.</td>
<td></td>
</tr>
<tr>
<td>Need for good communication, plain English.</td>
<td>Need for clear explanations, including about consent.</td>
<td></td>
</tr>
<tr>
<td>Need for interpreting and translation.</td>
<td>Need for interpreting and translating.</td>
<td></td>
</tr>
<tr>
<td>Need for awareness of and respect for requirements of religions and beliefs.</td>
<td>Need to ensure specialist centre has information on each patient’s religious or cultural requirements, including in relation to end of life, and relevant expertise and knowledge available.</td>
<td></td>
</tr>
<tr>
<td>Views of traditionally under represented groups from <em>Consulting the Capital</em></td>
<td>Views of traditionally under represented groups from <em>The shape of things to come</em></td>
<td></td>
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<tr>
<td>---</td>
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<td></td>
</tr>
<tr>
<td>Need for support and respect for carers.</td>
<td>Concern that the level of carer allowance is an insult (£53.10 per week with loss of entitlement to any other benefit).</td>
<td></td>
</tr>
<tr>
<td>Sufficiently knowledgeable staff needed people with all long term conditions.</td>
<td>Groups referred specifically for the need for expertise on diabetes and sickle cell.</td>
<td></td>
</tr>
<tr>
<td>People with mental health problems.</td>
<td>A group of people with mental health problems expressed areas of anxiety including anxiety over consent forms - <em>we need more communication and explanation when we are being asked to sign a consent form.</em></td>
<td></td>
</tr>
<tr>
<td>Facilities for all disabled patients and visitors.</td>
<td>Ensuring specialist centre has information on each patient’s long term health problems and disabilities, and relevant expertise and knowledge available.</td>
<td></td>
</tr>
<tr>
<td>Facilities for patients and visitors with learning difficulties.</td>
<td>One suggestion was that there should be a specialist Learning Difficulty service within the specialist services, with somebody who could explain what is happening to people with a learning disability. One person stated that people with learning difficulties die in hospitals because they are not taken seriously and given appropriate medical care.</td>
<td></td>
</tr>
<tr>
<td>For people with low incomes, support such as concessionary travel to enable families to visit.</td>
<td>Concern about the consequences for family, friends and carers confronted with long travel times to visit; questions about facilities for families, friends and carers at the specialist hospitals.</td>
<td></td>
</tr>
<tr>
<td>Importance of non-discriminatory and sensitive staff and processes for various groups (disability, culture, gender, sexual orientation, gender reassignment, age).</td>
<td>Tackling prejudice and discrimination among NHS staff. Staff training at all levels.</td>
<td></td>
</tr>
<tr>
<td>For all groups susceptible to stigma - respectful staff, accessible services, equal access to services, confidentiality.</td>
<td>Tackling prejudice and discrimination among NHS staff. Staff training at all levels.</td>
<td></td>
</tr>
</tbody>
</table>
### 4.6.2 Common Issues across more than one Group

Table 5 shows issues raised by more than one group.

<table>
<thead>
<tr>
<th>COMMON ISSUES</th>
<th>MAJOR TRAUMA</th>
<th>STROKE</th>
</tr>
</thead>
</table>
| **Concerns relating to ambulance journey times to Major Trauma Centre or HASUs.** | • Associates (Women)  
• BME (1/2)  
• Carers (1/3)  
• Diabetes (1/2)  
• Disability (2/2)  
• Learning Disabilities (3/5)  
• Older People (1/5)  
• Young People (1/2) | • Asian (Women)  
• Carers (2/3)  
• Older People (1/2) |
| **Concerns relating to access for family and friends to distant hospital**    | • BME (1/2)  
• Disability (1/2)  
• Older People (1/5)  
• Refugees | • Hindu  
• Older People (2/5)  
• Refugees  
• Stroke (1/3) |
| **Concerns over access to aftercare for patients, including local rehabilitation services.** | • Older People (1/5) | • Black British (Long Term Condition)  
• Carers (1/3)  
• Disability (1/2)  
• Ex-Offenders  
• Hindu  
• Jewish (Care Home Residents)  
• Mental Health  
• Older People (2/5)  
• Stroke (1/3) |
| **Concerns over what happens to patients who have strokes in a hospital that is not a stroke unit** | | • Disability (1/2)  
• Stroke (1/3)  
• Women (Mental Health) |
| **Concerns over funding and affordability of proposals** | • Carers (2/3)  
• Low Incomes (1/2)  
• Older People (1/5) | • Long Term Conditions (1/2) |
**TABLE 5 - ISSUES COMMON TO MORE THAN ONE GROUP**

<table>
<thead>
<tr>
<th>COMMON ISSUES</th>
<th>MAJOR TRAUMA</th>
<th>STROKE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Common Issues raised</td>
<td>Groups Who Raised Issue</td>
<td>Groups who raised Issue</td>
</tr>
</tbody>
</table>
| Concern that geographic spread of locations of Trauma Units or HASUs not evenly spread, too centralised for outer London patients | ▪ Limited Basic Skills  
▪ Young People (2/2) | ▪ Buddhists  
▪ Jewish (Care Home Residents)  
▪ Low Incomes (1/2)  
▪ Women (MH)  
▪ Young People (2/2) |
| Concerns over what happens if major incident takes place or Major Trauma Units are full | ▪ Black British (LTC)  
▪ Carers (1/3)  
▪ Disability (1/2)  
▪ Older People (1/5)  
▪ Young People (2/2) | |
| Concern that interpreters and staff with cultural awareness are present in the emergency ambulances and/or the Trauma and Stroke Centres | ▪ Low incomes (1/2)  
▪ Limited Basic Skills  
▪ Muslim | ▪ Low incomes (1/2)  
▪ Limited Basic Skills  
▪ Muslim |

Words in brackets indicate the second characteristic of the group named (i.e. an Asian group of women)  
* Numbers indicate the number of organisations out of the total cluster covering the group (i.e. 1 BME group of the 2 BME groups consulted through community organisations, by the PCTs)
### 4.6.3 Group Specific Issues

Table 6 provides a further breakdown of the issues raised by individual groups that are specific to their needs.

<table>
<thead>
<tr>
<th>Category (additional category, no. grps who raised)</th>
<th>Specific Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asian (female)</td>
<td>Facilities to support relatives to stay by patient is very important for the Asian community</td>
</tr>
<tr>
<td>Black British (Long Term Condition)</td>
<td>Stroke units need specialist knowledge of link between sickle cell and strokes</td>
</tr>
<tr>
<td>Buddhists</td>
<td>Staff need to understand specific Buddhist needs when a patient dies e.g. a private space for relatives, sometimes they will need to chant, it is important that the patients body is not removed too quickly.</td>
</tr>
<tr>
<td>Care home residents</td>
<td>Want services to be based in local hospitals</td>
</tr>
<tr>
<td>Carers (3 incl. stroke survivors)</td>
<td>Concerns for post hospital treatment, follow up, intermediate care, social services, rehabilitation and support for carers</td>
</tr>
<tr>
<td>Diabetes (2)</td>
<td>Require understanding of long term conditions and specialist knowledge of Diabetic care within stroke team to resume insulin regime as soon as possible</td>
</tr>
<tr>
<td>Disability (2)</td>
<td>Concerns about patients who have a stroke whilst in hospital and whether staff will recognize symptoms.</td>
</tr>
<tr>
<td>Hindu</td>
<td>Importance of services and treatment to be close to home for family and friends to support recovery.</td>
</tr>
<tr>
<td>Learning Disability (5)</td>
<td>Patients with learning difficulties need someone in each unit who can explain what is happening. There should be a specialist Learning Disability service as part of Urgent Care Services. All staff should be trained by people with learning difficulties</td>
</tr>
<tr>
<td>Low incomes (2)</td>
<td>Proposed locations of Centres/units too centralised for outer London patients and their families</td>
</tr>
<tr>
<td>Mental Health</td>
<td>Paramedics and Trauma Centre/Stroke Unit staff must be trained on mental health issues to support patients</td>
</tr>
<tr>
<td>Older people (5)</td>
<td>Concerns about support systems aftercare and rehabilitation services be in place when patient moves back to local hospital or home</td>
</tr>
<tr>
<td>Refugees</td>
<td>Concern about access for family visits if Centre far away</td>
</tr>
</tbody>
</table>
### TABLE 6 - ISSUES RAISED SPECIFIC TO NEEDS OF A GROUP

<table>
<thead>
<tr>
<th>Category (additional category, no. grps who raised)</th>
<th>Specific Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stroke (3)</td>
<td>Concern that specialised services (rehabilitation phase) are not adequately provided for and that carers’ ability to get to the hospital be considered especially as so many are older people</td>
</tr>
<tr>
<td>Women (mental health)</td>
<td>That local services might by closed, causing anxiety</td>
</tr>
</tbody>
</table>

### 5. LIMITATIONS

In some cases, the information contained in the reports was thin. To supplement the forms received we telephoned PCTs to get additional information but in some cases, this was not available. 4 of the PCTs, who consulted a total of 10 groups, did not use the forms that we provided. This may have increased the number of ‘no views recorded’ for some of the questions. The number of ‘no views recorded’ by question ranged from 8 for the proposal for Stroke Care through 10 on the proposal for Trauma Networks to 24 for proposed locations for TIA services. We only have the evidence of the forms to judge the adequacy of consultation process.

### 6. CONCLUSION

Using the consultation document, *The shape of things to come*, and the Resources pack developed by Health Link, PCTs and Article 13 have consulted a wide range of traditionally under represented groups across London on proposals for major trauma and stroke services. The PCTs and Article 13 consulted 46 groups, covering 1,294 people and almost all the categories identified as priority traditionally under represented groups for consultation.

The consultation has found overall support for all the proposals for major trauma and stroke care contained in *The shape of things to come*.

Despite the number of ‘no views recorded’ the findings show that a majority of groups supported the recommendations of *The shape of things to come* subject to a range of doubts and reservation, summarised below. The groups appear to have given stronger support for the proposals for major trauma than for those for stroke care, but this may simply reflect the larger number of groups for whom no views were recorded in the case of stroke care. A slight majority of groups did not comment on the criteria for decision making, but a very large proportion of those who did comment supported one or more of the criteria.

Groups often expressed doubts, reservations and concerns, even when they supported a proposal. Many of these were similar to those reported in Health Link’s original Consultation with ‘Traditionally Under Represented’ Groups on the Healthcare for London Proposals (2008):
- **Loss of Services:** The fear that the new services will result in hospital closures and a reduction in access to hospital services persists.

- **Travel Times:** A persistent anxiety is about ambulance travel times, their impact on the recovery of patients and whether they can consistently meet the target times. *The shape of things to come* addressed both these concerns with evidence that both these concerns are being met (the benefits of improved treatment outweighing the increase in travel time anticipated, and the ambulance services’ own records indicating that the target times will be achieved. A number of groups remained sceptical, particularly about meeting the target times.

- **Families, Friends and Carers:** The new pattern of services may mean that some patients will be in hospitals further away from homes. Concern about how families, friends and carers will cope with this has persisted through both consultations. Low incomes, disability and older age could make visiting difficult for some people. Groups have wondered what facilities there will be for visitors and carers in the new centres. *The shape of things to come* did not discuss these issues. A facilitator of one group reported that one hospital was training specialist nurse coordinators to help support relatives. So it seems that some thought may be being given to the needs of relatives at least at some centres. The role of carers received attention in the earlier Health Link consultation with traditionally under represented groups (*Consulting the Capital*) and in Healthcare for London’s own pre-consultation engagement with major trauma and stroke patients and carers in preparation for *The shape of things to come*. The PCTs consulted groups of carers in their consultations, but generally the carers focused more on the proposals than on their own role in the services.

- **Paramedic Skills:** A number of groups commented on the crucial role that paramedics will play in the new arrangements. In the earlier consultation some groups expressed scepticism about their skills. *The shape of things to come* notes the importance of relevant skills for paramedics and the ambulance service more widely, and indicates that further training is being put in place.

- **Communication:** A number of groups have referred to the continuing importance of clear communication in plain English, with interpreting and translation as necessary.

- **Long Term Illness or Disability:** Groups recognised that patients being treated in the new centres for major trauma or stroke will sometimes have long term illness or disability and were concerned that staff in the centres need to be aware of the long-term conditions of individual patients and take account of these in their treatment.

- **Groups Vulnerable to Prejudice or Stigma:** Discrimination and prejudice may occur in relation to culture, religion, race, gender, sexual orientation, gender reassignment, age etc. For example, some religious groups, there are specific requirements in relation to end of life. Groups with learning difficulties, mental health problems etc. felt that they are sometimes subjected to discrimination and prejudice within the NHS.
• **Capacity:** Some groups raised concerns about the capacity of the new services to meet the demands, with one noting that major trauma centres could themselves become targets for terrorists in a concerted attack.

Compared with our earlier consultation with traditionally under represented groups in relation to *A Framework for Action*, this consultation on *The shape of things to come* has demonstrated much more substantial support for the recommendations. Nevertheless, there are doubts and reservations, many of which have persisted from the earlier consultation.