

INCREASING RESPONSE RATES AMONGST BLACK AND MINORITY ETHNIC AND SELDOM HEARD GROUPS

REPORT OF A CONSULTATION WITH STAKEHOLDERS
ON INCREASING RESPONSE RATES TO THE NATIONAL
INPATIENTS SURVEY

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making patients' views count

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1 Introduction

1.1 Background

This paper summarises a consultation with stakeholders about increasing response rates amongst Black and minority ethnic and seldom heard groups to the NHS acute inpatient survey. Although the focus is acute surveys, the work has implications for other surveys in the patient survey programme and included consultation with some primary care trusts.

The context for this work is set out in detail in a separate report.² In summary, it is a response to concerns about variations in response rates between different trusts groups and different groups, particularly Black and minority ethnic groups.³

The consultation was conducted by the Acute Co-ordination Centre at the Picker Institute on behalf of the Healthcare Commission as part of the development work for the NHS acute patient survey programme. There are four main strands to this work to increase response rates amongst Black and minority ethnic and seldom heard groups:

1. A comprehensive literature review
2. A consultation with stakeholders
3. Importance studies, testing and piloting questionnaire with Black and minority ethnic groups and seldom heard groups
4. Work to pilot and evaluate some new initiatives.

1.2 Literature Review

The literature review presents evidence in relation to five main aspects of increasing response rates: context, response bias, barriers to participation, strategies for increasing participation and measuring the impact of these strategies in practical studies.

Three main barriers to participation in postal surveys were identified: disengagement, poor literacy and a lack of contact information. Strategies have been proposed in relation to each of these to increase response rates and a number of organisations have

² Sheldon H, Graham C, Potheary N and Rasul F (2007) Increasing response rates amongst black and minority ethnic and seldom heard groups – a review of literature relevant to the national acute patients' survey. Oxford, UK: Picker Institute Europe. Draft internal report. A summary of this work can be found at:

http://www.nhssurveys.org/docs/Inpatient_Survey_2007_Increasing_response_rates8.pdf

³ Smith P (2006) Review of Black and minority ethnic coverage in the Healthcare Commission's patient survey programme

http://www.nhssurveys.org/docs/Review_BMEcoverage_HCC_surveys.pdf

developed guidelines. There is however very little empirical evidence available which measures the impact of these strategies in practice.

A summary version of the review is available on www.NHSSurveys.org. The full review will be available on the website in April 2007.

The summary version of the literature review was distributed to stakeholders involved in the consultation to stimulate discussion during meetings.

2 The stakeholder consultation

2.1 Inviting stakeholders to take part

Information about the work to increase response rates amongst Black and minority ethnic groups and seldom heard groups was widely disseminated and participation invited in early Summer 2006. Details were sent to all Race for Health PCTs and to all Trust communications staff via Healthcare Commission electronic bulletins. In addition, a number of trusts who had previously expressed concerns about the relevance of the survey methodology for their patient population were directly approached and invited to take part.

Twelve trusts expressed an interest in becoming involved in the consultation and meetings were held with staff, patients and their representatives at nine of these. Details of these meetings are set out in Appendix 1.

Information about the work to increase response rates to the NHS inpatient survey was sent to a broad range of other stakeholders during July 2006. Most initial contact was by email with follow up telephone contact in some cases. Stakeholders were identified from relevant databases (eg The Market Research Society) and through a cascade approach. Details of contacts with organisations outside the NHS are set out in Appendix 2.

A total of twenty nine meetings involving approximately 160 participants were held between July 2006 and January 2007. In addition one letter was received from an acute trust and eleven emails were received with written comments. Meetings were held over the telephone and face to face on a one to one basis and in small and large groups. Most of the meetings were set up specifically to discuss response rates to the inpatient survey. Some however addressed the topic as part of the agenda of an established group meeting. Participants included patients, patient groups and their representative organisations, and NHS staff. These staff worked in a range of roles in NHS acute trust and primary care trusts.

2.2 Format of the meetings

Discussion in the meetings was initiated by a presentation from the author using the findings of the literature review. Comments and feedback from all participants was encouraged using a non judgemental open approach. However, as this was a consultation the limitations of the scope for change were explained where appropriate. These limitations are set out in a separate document.⁴ In summary, they relate to a commitment to maintaining continuity and validity in the inpatient survey methodology.

⁴ See footnote 1 above

2.3 Output from the consultation meetings

A report setting out comments made by all the stakeholders during the consultation was sent to the Healthcare Commission on 25 January 2007 and was discussed at a meeting with them on 1 February. This contained a preliminary analysis grouping comments into themes under fourteen broad headings.

This report sets out further analysis to summarise each of the fourteen themes. It also sets out the response of the Acute Co-ordination Centre to suggestions made by stakeholders for changes to the survey methodology.

Plans for piloting initiatives and conducting further work are contained in each section where relevant. These actions were agreed with the Healthcare Commission at a meeting on 22 February 2007. They are set out in a separate section – section 4.

2.4 Next stages

- Distribution of Acute Co-ordination Centre and Healthcare Commission response to stakeholders
- Invitation to trusts to be involved in pilot and development work
- Implementation of pilot and development work.

3 Thematic analysis of comments made during the consultation

3.1 General comments about response rates

- Outside of London most trusts consulted were content with their overall response rate and their response rate for Black and minority ethnic groups
- Trusts with response rates far below the national average were concerned that their results were not a true reflection of the views of their patient population; they were not however surprised that the methodology resulted in low response rates amongst their patients groups; there was a view that little could be done to increase response rates to a postal survey; some groups regarded the postal survey as inappropriate for gathering the views of Black and minority ethnic groups and diverse communities; self completion surveys were regarded as inappropriate in areas of high deprivation where it was likely that many would struggle to communicate in writing
- Some groups expressed concern that the survey methodology is a one size fits all methodology and it does not work with diverse communities
- Some groups suggested alternative approaches to collecting patient feedback (see Section 3.9 below)
- Diversity, deprivation, poor literacy and highly mobile populations were put forward as the main reasons to explain low responses in certain trusts; some of the trusts consulted had 70% Black and minority ethnic groups population
- Two trusts expressed concerns that response rates are falling on a year by year basis.

Acute Co-ordination Centre Response:

- Trusts need to be proactive in terms of contacting us to discuss any concerns they have about response rates
- The current methodology is based on recommended guidelines for maximising responses to postal self completion questionnaires; during the 2007 survey we will be piloting and testing further initiatives which the evidence suggests may increase response rates
- The survey guidance indicates that trusts may wish to do further qualitative work to obtain feedback from specific patient groups. If the Black and minority ethnic groups patient population at a particular trust is very small then it is outside the remit of this survey to conduct analysis of those groups. Trusts in this position are advised to contact us for further guidance
- Falling response rates to postal surveys is an on-going concern across the industry. However, response rates to the 2006 inpatient survey are only very slightly lower than for 2005. Additionally, we have recently undertaken a survey

using this approach and a similar survey instrument that achieved a response rate of 88%.

3.2 Poor patient contact information as a reason for low response rates

- Poor contact information for their highly mobile patient populations was regarded as a problem in some groups
- This was regarded as a particular problem for patients not registered with a GP who access hospital services via A&E, the minor injuries clinic or the GP walk-in centre; it was suggested that it would be useful to know how many of the inpatient survey sample were admitted via these routes and whether the figures were different in other parts of London or other parts of England
- Trusts in less deprived areas did not regard this as a problem
- There was concern in one group that the method did not reach people of no fixed abode.

Acute Co-ordination Centre Response:

- Patients from Black and minority ethnic groups are significantly more likely to have questionnaires returned undelivered. Analysis of questionnaires returned undelivered in the 2006 Inpatients survey showed that slightly more than 2% of questionnaires sent to Black and minority ethnic groups patients were returned compared with just under 1% of those sent to white patients.
- This is an issue for Trusts to address in collecting contact information for patients and in using the NHS Strategic Tracing Service before mailing to ensure that addresses are still current
- Examination of route of admission to hospital to investigate the characteristics of patients admitted through A&E could be the first stage of a follow up study (see Section 3.7 below).

3.3 Disengagement as a reason for low response rates

Stakeholder definitions of disengagement

- Disengagement was defined here as a lack of engagement with the survey process; BME groups and younger people were thought to be less likely to be engaged with the survey process
- The questionnaire was thought to be less salient to young people than older people who are more likely to have a greater need for and experience of healthcare
- Completing a questionnaire requires conformity; young people are less likely to show conformity than older people who grew up in system where you did what you were told

- A number of stakeholders suggested that Black and minority ethnic groups were more likely to be disengaged with the survey process because evidence suggests that they are more likely to have had negative experience of health services, particularly because of language and communication difficulties
- It was suggested that Black and minority ethnic groups, particularly refugees and asylum seekers tend to be more suspicious of government and of being over monitored
- Black and minority ethnic groups were thought to have more concerns about the confidentiality of the data collected and to have more concerns about the data being used to check for eligibility for services; young men were thought more likely to have been admitted via A&E for reasons that they may have serious concerns about the incident being confidential
- Patients generally were thought to have a lack of confidence that their input and the survey findings generally would be put to good use
- It was suggested that people living in London and in areas of high deprivation had less time to complete a questionnaire
- It was suggested that the questionnaire may not address issues that are of relevance to Black and minority ethnic groups eg language and interpreting, respect for religious beliefs; more consultation needed with trusts and with patients regarding the content of the questionnaire
- Patient groups raised specific concerns about questions 71 (age of leaving full time education) and 75 (ethnic group)
- Questionnaire fatigue was a further dimension of disengagement mentioned in two groups
- Two groups expressed concerns that people will only complete a questionnaire if they had a particularly good/bad experience, or were frequent service users.

Stakeholder suggestions for addressing disengagement

- South Essex Partnership NHS Foundation Trust described how they have been working in partnership with Essex Race Equality Council and locality Black and Ethnic Minority Partnership groups to prepare the grounds for surveys by engaging with Black and minority ethnic groups communities and service user networks and explaining the purpose of the survey, the reason for collecting particular information and what it will be used for
- Patients need to be reassured that information they provide will be confidential
- Patients need to be convinced that there is something to gain from completing a survey ie they need to feel ownership; sending questionnaire from trust rather than from NHS was suggested as one way of addressing this issue; raising awareness through local media was also suggested
- Providing feedback and evidence about the changes that have been made as a result of the survey were also suggested to create ownership
- Letters to patients should refer to the hospital by name rather than just to the trust name
- The sampling process may exclude many patients who wish to comment on the services they received; sample should be extended
- Patients receive questionnaires too long after discharge and therefore are less likely to see any purpose in completing it; it was suggested that questionnaires should be distributed at discharge.

Acute Co-ordination Centre Response: (1) Proposed changes

- We will improve survey guidance for trusts on raising local awareness of survey eg templates to disseminate information to local community organisations
- The survey methodology makes providing advance publicity to patients at discharge difficult. We are however considering ways that this might be achieved; for example, in the 2007 survey of maternity service users we provided posters for display in all units
- For the 2007 inpatient survey we will pilot addressing the patient by name in the covering letter
- We are currently exploring ways to improve processes for providing patients with feedback about the survey findings
- We are currently exploring the implications of extending the fieldwork period to give people more time to complete the questionnaire; preliminary analysis of 2006 inpatient survey data suggests that this may increase response rates amongst Black and minority ethnic groups
- An importance survey was conducted with patients during 2006; the sample included a Black and minority ethnic group boost. Data gathered from this will inform the content of the 2007 survey.
- Acute Co-ordination Centre will assess the use of data from Q71 in collaboration with stakeholders
- Other acute surveys have included introductory text to the demographic section explaining why information is being collected; this will be added to the questionnaire in the April 2007 pilot and the impact on item non response will be reviewed.

Acute Co-ordination Centre Response: (2) Other comments on issues relating to disengagement

- Questionnaire fatigue: there is a general fatigue with unsolicited approach, but this is not an argument in itself against postal surveys
- Saliency: Groves et al (2000)⁵ provide evidence that individual response to a survey is determined by the relevance of the survey and what the individual stands to gain. They found that offering incentives did increase response rates amongst those less likely to take part.⁶ At present the Acute Co-ordination Centre does not support offering patients incentives to complete a questionnaire because of the financial implications involved.
- Sample size: survey guidance has always included clear information about sample sizes; 850 has been shown to be a sufficient sample size to enable generalisations to be drawn; a limited amount would be gained by increasing the sample size and it would not improve response rates.

⁵ Groves RM, Singer E and Corning A. 'Leverage-saliency theory of survey participation: description and an illustration.' *Public Opinion Quarterly* (2000) 64:299-309

⁶ Tourangeau R. 'Survey research and societal change.' *Annual Review of Psychology* (2004) 55:775-801

<http://list-socrates.berkeley.edu/~maccoun/Tourangeau2004.pdf>

Last accessed 22/03/07

- Questionnaire placement: the guidance recommends questionnaires are sent out as soon after discharge as possible; see response at section 3.10 below to suggestion for exit/discharge survey
- Questionnaire content: trusts do need to be proactive in informing the Acute Coordination Centre of any concerns they have about questions; they also need to respond to any consultations that the Coordination Centre initiates.

3.4 Communication barriers as a reason for low response rates

- Many stakeholders suggested that the questionnaire was too long and daunting to patients with poor literacy skills
- The covering letter and instructions were thought to be too complex
- Audio questionnaires should be provided for patients with a visual impairment
- Older people are more likely to experience cognitive impairments making the questionnaire difficult to complete; people with learning disabilities may also experience cognitive barriers to completion
- Many stakeholders referred to large numbers of their patient population who do not speak English and would therefore struggle to complete a questionnaire
- Many stakeholders spoke of high levels of functional illiteracy in their patient populations, eg said to be as much as a third of the population in some areas.

Acute Co-ordination Centre Response:

- **Length of questionnaire:** development work for the 2002 inpatient survey showed that patients were as likely to complete a 12 page questionnaire as a 4 page one
- **Language used in questionnaire and covering letter:** the questionnaires are cognitively tested before each implementation. For the 2007 survey the covering letter and questionnaire will be tested and piloted to ensure that these are easily understood by patients; cognitive testing will be conducted with patients from Black and minority ethnic groups
- **Patients with a visual impairment:** the RNID have suggested sending questionnaires out on CD; however, detail of visual impairment is not captured on the sample frame so we would not know who to send CDs to. The provision of a telephone helpline to include those with a visual impairment seems a satisfactory and more personal approach
- Providing the questionnaire in different formats to meet the needs of people with communication impairments (eg translations and simple language / pictorial format): until trusts collect information about patients' language support needs which can be linked to sample data, sending questionnaires in alternative formats is problematic; carers can complete questionnaires on the patients behalf where appropriate and this information is clearly set out on the front page of the questionnaire; personal support is also provided through the telephone helpline to help patients with language support needs to complete the questionnaire

- **Recommendations for gathering feedback from patients with communication impairments:** it is believed that the current arrangements for providing support over the telephone for people with literacy difficulties is an appropriate approach to including these groups in a national standardized survey; trusts wishing to explore the specific experiences of patients with communication impairments will get more informative data from targeted work with these groups.

3.5 Addressing communication barriers to completion of questionnaire – translating questionnaires

- Stakeholders expressed conflicting views regarding the effectiveness of translating the questionnaire into community languages; some saw it as necessary to obtain feedback from patients who do not speak English; others believed that it was not a useful approach to involving people who were not literate in the English language .

Acute Co-ordination Centre Response:

- The Acute Co-ordination Centre accepts that some stakeholders feel very strongly that translating questionnaires is the way forward and we are interested to explore the issues involved with those trusts in more depth. We feel that without information about language spoken included in the sample frame, the practical difficulties of implementing translated questionnaires prohibit testing this approach at present.

3.6 Support mechanisms to overcome barriers to completion

- Some stakeholders were happy with existing arrangements to provide patients with support to complete the survey; others felt that telephone helplines were not an effective way to provide language support; it was suggested that the current take up of language line support was extremely low compared with the numbers who required language support
- It was suggested that the covering letter and questionnaire instruction sheet needed to make it clear as to whether the carer can complete the questionnaire on the patients' behalf
- Stakeholders suggested a number of face to face approaches by which patients could be supported in completing a questionnaire eg by GPs and by hospital staff, including PALS and interpreters; by independent community researchers and by community organisations
- Group support sessions were suggested as an effective way of meeting the communication support needs of patients eg by providing sessions in relevant community languages.

Acute Co-ordination Centre Response:

- Carers can complete questionnaires on the patients' behalf where appropriate; this information is clearly set out on the front page of the questionnaire.
- The Acute Coordination Centre discourages GPs and other healthcare staff providing help to complete questionnaires because of the impact of interviewer bias.
- The Stroke Survey linked with carer organisations to provide support to patients in completing questionnaires; ACC could look this year at working more closely with trusts in terms of facilitating support from community organisations; the guidance will include more specific advice on this issue.

3.7 Finding out more about non responders

- Most stakeholders were interested in a non responders study and thought this would provide useful information; follow up contact by telephone was regarded by some as the most effective mode of conducting the non response study; one of the patient groups regarded the telephone as a poor way of making follow up contact with non responders; group sessions with appropriate language support was another method recommended.

Acute Co-ordination Centre Response:

- We are strongly supportive of the principle of conducting work to explore the characteristics of non responders, however there are ethical, practical and financial issues that need to be resolved before this can occur. Previous attempts to secure ethical approval for a non response study of the patients survey have been unsuccessful.

3.8 Other approaches to increasing survey response rates

- A number of stakeholders suggested targeted work with groups known to be low responders as a way of increasing response rates
- Black and minority ethnic groups boost samples were also recommended.

Acute Co-ordination Centre Response:

- The survey guidance already suggests that targeted work may be appropriate; trusts are encouraged to contact the Acute Coordination Centre for advice on conducting such studies
- The survey guidance indicates that trusts can use boost samples and they can contact Acute Coordination Centre for help; but it should be recognised that the response rate to a boost sample will be the same as for the main sample (or for that cohort of the main sample) and so any response bias will still be present.

3.9 Alternative parallel methods to obtain patient feedback

- A number of stakeholders thought that parallel methods were needed to gather data from Black and minority ethnic groups and other seldom heard groups; they believed the data gathered could then be used in conjunction with that from the national survey
- Some stakeholders preferred face to face qualitative methods of obtaining feedback from patients
- It was suggested that some sort of national pool of trained facilitators could be developed to run sessions around the country
- Using community organisations to access patients was also suggested
- Electronic methods were thought to be a more appropriate approach to securing participation of young people
- Some stakeholders preferred the use of telephone surveys to obtain patient feedback because they overcome language and literacy barriers.

Acute Co-ordination Centre Response:

- We are conducting a separate review of the use of mixed modes in the inpatient survey; preliminary findings suggest reservations about its likely impact; measures to improve communication may be more effective eg text messages to remind people to complete the questionnaire
- Any qualitative parallel work should be arranged by the trust; it is not feasible to arrange large scale qualitative work on a national basis
- Trusts carrying out qualitative work need to be aware of the impact of interviewer and group effects
- The use of alternative technologies has been the subject of a separate review; preliminary work suggests that those who reply by the internet would have replied anyway
- Telephone surveys are not seen as feasible at present because of mode effects and cost; evidence obtained from hospitals suggests that telephone numbers for patients are not routinely available and that postal address data appears to be more reliable.

3.10 Alternative placement of survey – exit and in hospital surveys

- Some stakeholders identified difficulties with timeframe of the sampling, arguing that patients memory has begun to fade by the time they receive a questionnaire
- Some trusts said that there was a long delay between any adverse event and the trust being able to do anything about it
- A number of stakeholders recommended an exit survey or a survey of patients while they are in hospital
- Some stakeholders argued that exit and bedside surveys would allow support to be provided where needed

- A number of trusts were using shortened versions of the questionnaire to obtain feedback from patients while they were in hospital; some of these also used alternative technologies to gather the data eg PatientLine and hand held devices.

Acute Co-ordination Centre Response:

- Analysis of response rates to the 2006 inpatient survey by date of discharges shows no apparent relationship between time since discharge and likelihood of response
- Trusts can reduce the delay by making use of early results from contractors
- The main difficulty with discharge surveys is that we lose the ability to send reminder letters. The survey guidance has advised trusts to select the sample from patients who were most recently discharged – this could be as little as two weeks prior to the initial mailing; trusts' ability to sample patients recently discharged is however limited by the speed with which they are able to obtain up-to-date records
- Interviewer bias means that face to face approaches are not recommended⁷
- Electronic bedside data collection is a good tool for a different task; it is not an appropriate way of conducting a national standardized patient survey.

3.11 Comments about reporting of results

- Further analysis of results would be helpful eg by Black and minority ethnic groups
- Some trusts said they would like to see their results compared with those of similar trusts
- Some trusts said the results were not useful to them eg is too much of an overview, results do not take account of recent improvements
- Benchmarking against trusts with a very different patient population does not provide the trust with useful information
- Need for overall review of purpose of survey.

Acute Co-ordination Centre Response:

- The Acute Co-ordination Centre has addressed these issues in a 2006 survey of acute trusts use of inpatient survey results; we will be providing a toolkit to assist trusts in use of results in 2007
- Information is available on the website for trusts to compare their results to similar trusts if they wish; the Acute Co-ordination Centre will issue a toolkit during 2007 to help them use this data
- Guidance does provide advice on how to do ward based analysis

⁷ Healthcare Commission (2005) 'A snapshot of hospital cleanliness in England - Findings from the Healthcare Commission's rapid inspection programme.

http://www.healthcarecommission.org.uk/_db/_documents/04021935.pdf

Last accessed 22/03/07

- The inpatients survey needs to be seen as a continuous process that enables change to be monitored over time; the Acute Co-ordination Centre are attempting to get results out faster; trusts can use contractor results to allow early identification of areas for action
- In the recent White Paper on primary and community care the Department of Health announced a review of the national patient survey programme⁸.

3.12 Expressions of interest in pilot and development work

- Most trusts involved in the consultation indicated an interest in involvement in pilot work and in a study of non responders.

3.13 Views about the development work to address poor response rates

- One stakeholder suggested that these issues are not new and questioned why they were only being addressed now
- Others welcomed that these issues were being addressed; the important role of the survey in providing improved market intelligence was emphasised
- One stakeholder questioned whether the extent of the variation in response rates warranted additional expenditure.

Acute Co-ordination Centre Response:

- Many of these issues have already been addressed; the Healthcare Commission has an explicit commitment to examine these issues in its Race Equality Action Plan and has asked us to look specifically at these issues in the development work for the 2007 and 2008 surveys
- Additionally, the patient survey programme is a huge programme of work in relatively early stages of development; there has not been time before to address many of the issues that we would like to address.

3.14 Other comments

- Many trusts have their own consultation mechanisms for consulting with Black and minority ethnic groups and seldom heard groups

⁸ Department of Health (2006) 'Our health our care our say: a new direction for community services'. London: The Stationery Office. Para 7.21
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_5684898
 Last accessed 22/03/07

- Some trusts have looked specifically at improving participation of Black and minority ethnic groups in their feedback mechanisms
- Obtaining feedback from carers is appropriate and necessary in cases where carers play a big part eg when people with learning disabilities or older people with cognitive impairments are in hospital
- Completeness of ethnic group data varied enormously between different trusts; the Department of Health are working with trusts to improve quality of data.

4 Recommendations

4.1 Increasing engagement with the survey process

- Improve survey guidance for trusts on raising local awareness of survey eg templates to disseminate information to local community organisations
- Consider ways to improve advance publicity
- Pilot addressing the patient by name in the covering letter in the 2007 inpatient survey
- Explore ways to improve processes for providing patients with feedback about the survey findings
- Explore the implications of extending the fieldwork period to give people more time to complete the questionnaire
- Use the findings of the 2006 importance survey to inform the content of the 2007 survey.
- Assess the use of data from Q71 (age of leaving full time education) in collaboration with stakeholders
- Pilot the addition of introductory text to the demographic section explaining why information is being collected and review the impact on item non response.

4.2 Communication barriers as a reason for low response rates

- Language used in questionnaire and covering letter: conduct cognitive interviews to test the content of the questionnaire with Black and minority ethnic patients.

4.3 Support mechanisms to overcome barriers to completion

- Provide more specific advice on how trusts can facilitate support from community organisations.

4.4 Finding out more about non responders

- We are strongly supportive of the principle of conducting work to explore the characteristics of non responders however, there are ethical, practical and financial issues that need to be resolved before this can occur.

4.5 Alternative parallel methods to obtain patient feedback

- We are conducting a separate review of the use of mixed modes in the inpatient survey; preliminary findings suggest reservations about its likely impact; measures to improve communication may be more effective eg text messages to remind people to complete the questionnaire.

4.6 Reporting of results

- Provide a toolkit to assist trusts in use of results in 2007
- Attempt to get results out faster.

Appendix 1: NHS Trust involvement in the consultation

Trust or area	Meetings held
1. Shrewsbury	<ul style="list-style-type: none"> ▪ Shropshire PCT Race Equality Committee: 29/01/07 ▪ Shropshire PCT Learning Disability Forum: 29/01/07 ▪ Shrewsbury and Telford Hospitals NHS Trust: 29/01/07
2. Leeds	<ul style="list-style-type: none"> ▪ Leeds University Hospital NHS Trust: Survey / PPI Survey Lead ▪ Meeting with Directors in Leeds: 31/10/06
3. Homerton Hospital NHS Trust	<ul style="list-style-type: none"> ▪ PPI Manager and Deputy Director of Nursing ▪ R&D Manager ▪ Board of Trust Governors: 06/12/06 ▪ PPI Committee: complete 7/11/06
4. Birmingham	<ul style="list-style-type: none"> ▪ South Asian Health Foundation, Department of Primary Healthcare, University of Birmingham, Birmingham City Hospital and Leicester University representatives: 3/10/06 ▪ PCT Public Health Officers: 3/10/06 ▪ University Hospitals Birmingham Trust Survey Leads: 4/10/06
5. Westminster PCT	<ul style="list-style-type: none"> ▪ Westminster PCT Head of Equalities ▪ PCT and St Mary's and Chelsea and Westminster Hospitals; BME Health Forum KCW: 5/12/06
6. Newham Hospital	<ul style="list-style-type: none"> ▪ Older People's Reference Group: 9/11/06 ▪ Diabetes Newham Group: 29/11/06 ▪ Newham Hospital Survey Lead: 12/12/06 ▪ Patient group: 12/12/06
7. Ealing Hospital	<ul style="list-style-type: none"> ▪ Head of PPI
8. St Georges Hospital Trust	<ul style="list-style-type: none"> ▪ Interest expressed, but no meetings held
9. Bradford	<ul style="list-style-type: none"> ▪ PCT Equalities Lead ▪ Hospital Trust Deputy Chief Exec and Diversity, PPI and Survey leads: 13/10/06
10. Bedford	<ul style="list-style-type: none"> ▪ Bedford Hospital Trust – Non-Executive Director: 27/07/06
11. Leicester	<ul style="list-style-type: none"> ▪ Interest expressed, but no meetings held
12. South Essex Partnership NHS Foundation Trust	<ul style="list-style-type: none"> ▪ Chief Executive – written response to consultation dated 27/11/06

Appendix 2: List of individuals and organisations consulted

Information about the work to increase response rates to the NHS inpatient survey was sent to a broad range of stakeholders during July 2006. Most initial contact was by email with follow up telephone contact in some cases. Stakeholders were identified from relevant databases (eg MRS) and through a cascade approach.

The following organisations were contacted directly:

- The Afiya Trust
- ARC – people with learning disabilities
- The Black Health Agency
- The Centre for Ethnicity and Health
- Centre for Evidence in ethnicity, health and diversity
- Centre for Research in Ethnic Relations, University of Warwick
- Commission for Racial Equality
- Commission for Social Care Inspection
- Help the Aged
- ICAR, Information Centre about Asylum and Refugees in the UK
- National Institute for Mental Health in England (NIMHE)
- National Network for Learning Disability Nurses (Access to Acute) interest group (19/07/06 and 29/01/07)
- National Patient Safety Agency (PPI Lead, 19/07/06)
- Policy Research Institute on Ageing and Ethnicity (PRIAE)
- Policy Studies Institute on Ageing and Ethnicity
- Refugee Council
- REU – promoting race equality in social support and social care
- The Runnymede Trust
- The South Asian Health Foundation
- TRIPOD (network of those with and working with learning disabilities).

Postings were made on electronic forum including:

- BMEspark
- CHAIN 1
- Refugee Health Network
- www.networks.nhs.uk
- BMEforum@nhsconfederation.org.

Written responses were received from:

- Jez Buffin (Centre for Ethnicity and Health, UCLAN) – Have network of over 1,000 Black and minority ethnic groups that can access
- Mark Johnson (Centre for Evidence in ethnicity, health and diversity) – personal comment and references provided
- Sophie Wainwright (Information Centre about Asylum and Refugees (ICAR), School of Social Sciences, City University) – references provided
- Peter Mansell (Patient Engagement and Involvement Director, National Patients Safety Agency)

- Elias Phiri (Sector Development Officer – African Communities, Terrence Higgins Trust)
- Sam Turner at PRIAE (Policy Research Institute on Ageing & Ethnicity)
- Commission for Social Care Inspection
- Raj Bhopal (University of Edinburgh)
- Paul Burns (Refugee and Asylum Seeker Link Work / Befriending Scheme, Mind in Harrow).

Meetings were conducted with:

- Safina Islam (Diversity) and Anna Coote, Jose King, Clare Dulap (Healthcare Commission, Patient and Public Engagement Team)
- Raymond Warburton (Equality & Human Rights Group, Department of Health)
- Anna D'Agostini (BME development officer, Help the Aged)
- Helen Hally (Director, Race for Health)
- Helen Dorr (Coordinator, National Family Carer Network (for people with learning disabilities))
- Dr Keith Meadows (Director R&D Tower Hamlets PCT)
- Rick Robson (National Access to Acutes (A2A) Network)
- Asmina Remtulla (Continence Advisor, Finchley Memorial Hospital)
- Kiran Patel and Pamaljit Gill (The South Asian Health Foundation) and Margaret Stone (Leicester University)
- Taking Part-Shropshire / Telford & Wrekin Self Advocacy group.

